CANCER, CROWNS, AND CRITICAL CARE

How my cancer diagnosis helped diagnose my life

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LEARNING OUTCOMES

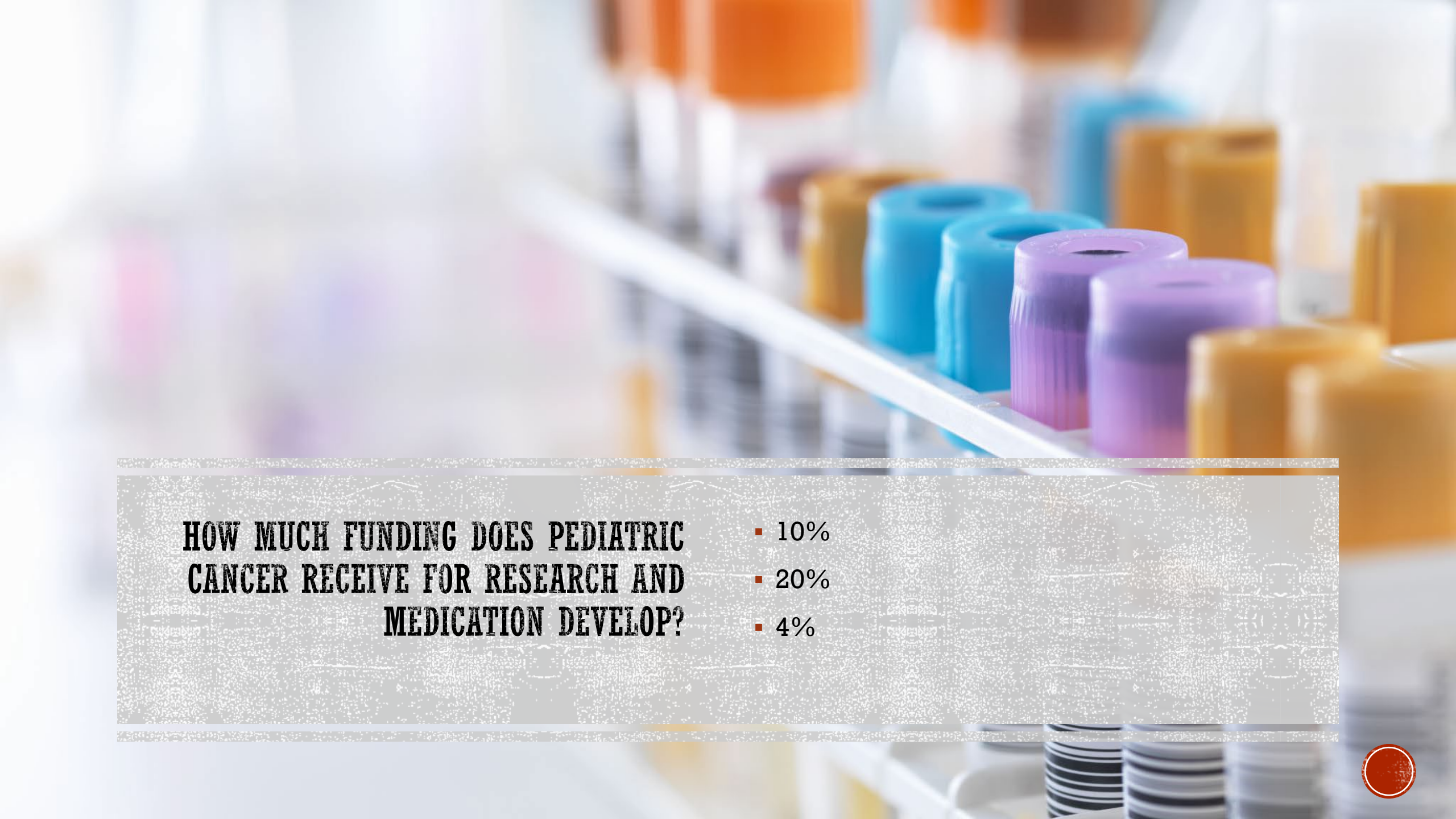
- Identify the challenges current pediatric cancer families and patients face.
- Develop an increased understanding on survivorship needs after treatment.
- Discover the challenging aspects of grief, loss, and bereavement of patients and families, as well as the loss experience of the health care professionals.

Desired Learning Outcome: Learner will have a greater understanding of pediatric cancer survivor needs after diagnosis and treatment

"THE DAY BEFORE MY CHILD WAS DIAGNOSED, I WASN'T A CANCER PARENT EITHER"

-UNKNOWN

- **Each year, approximately 400,000 children and adolescents of 0-19 years old are diagnosed with cancer (worldwide).**
- **The most common types of childhood cancers include leukemias, brain cancers, lymphomas and solid tumors, such as neuroblastoma and Wilms tumors.**



HOW MUCH FUNDING DOES PEDIATRIC CANCER RECEIVE FOR RESEARCH AND MEDICATION DEVELOP?

- 10%
- 20%
- 4%

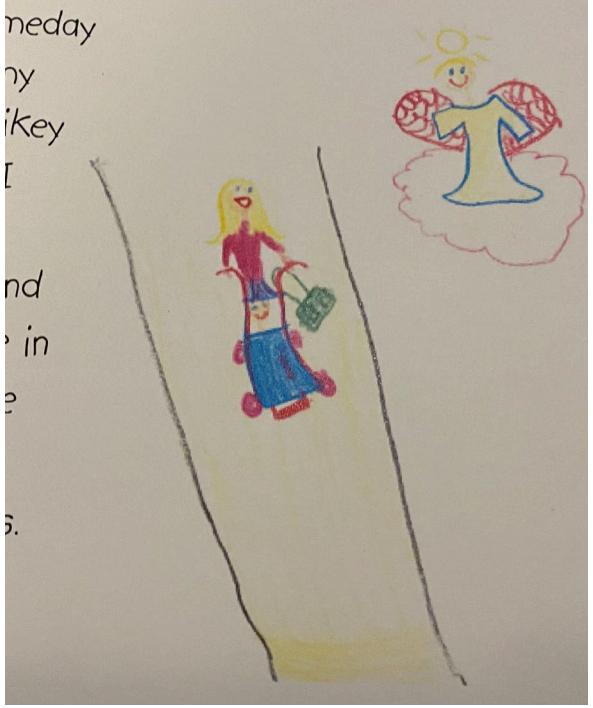
EVERYDAY 43 CHILDREN (AGES 0-19) ARE DIAGNOSED WITH CANCER

A: Every 5 minutes

B: Every 3 minutes

C: Every 10 minutes

D: Every hour

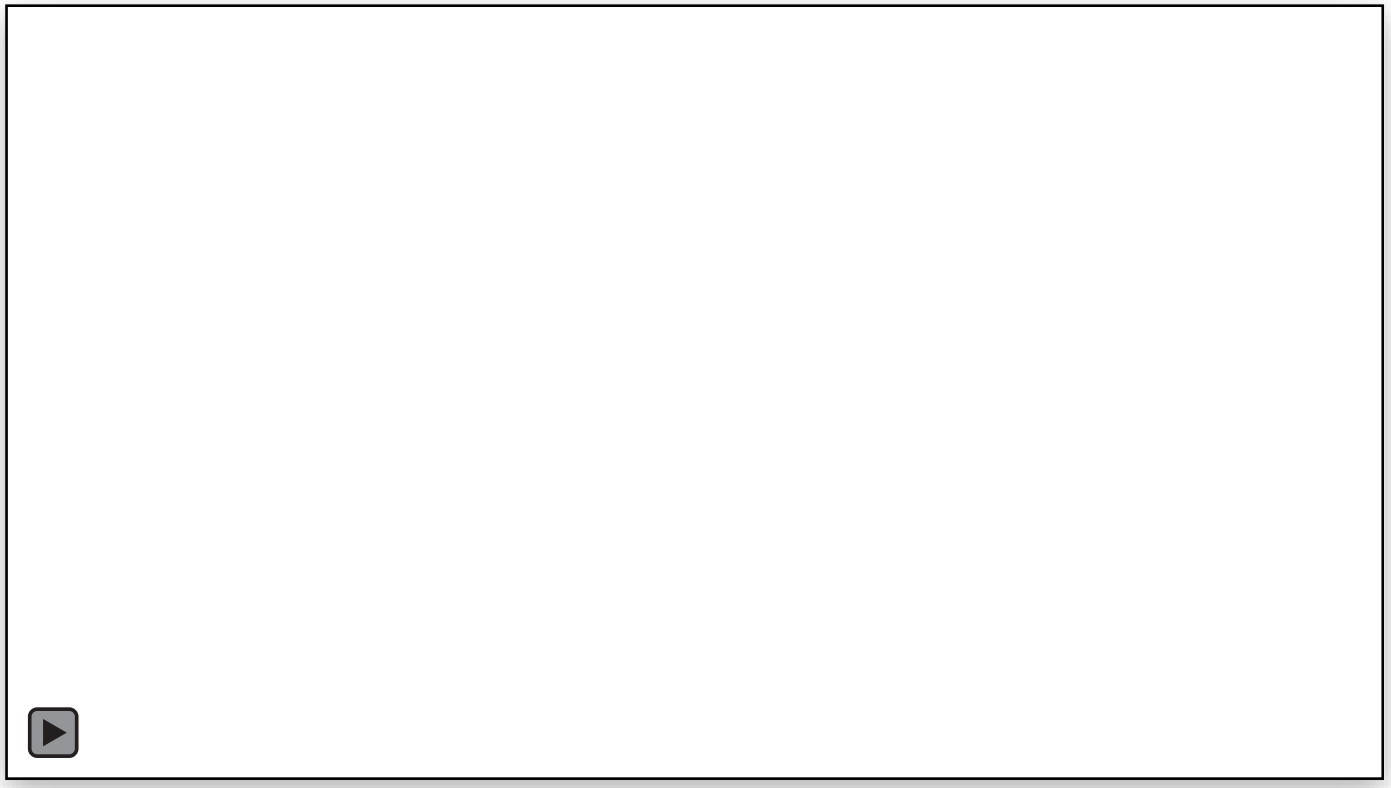


“CHILDREN AND ADOLESCENTS WITH CANCER MAY WISH TO TALK ABOUT THE MEANING OF BEING ILL, PARTICULARLY PROGNOSIS; AND CARE TEAM INVOLVEMENT IN THESE CONVERSATIONS MAY BE IMPORTANT FOR INDIVIDUAL CHILDREN AND PARENTS.”

APRIL 1999

From big sister

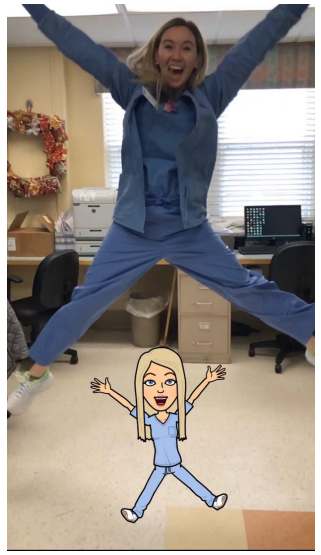
To cancer patient



2013 MISS RI

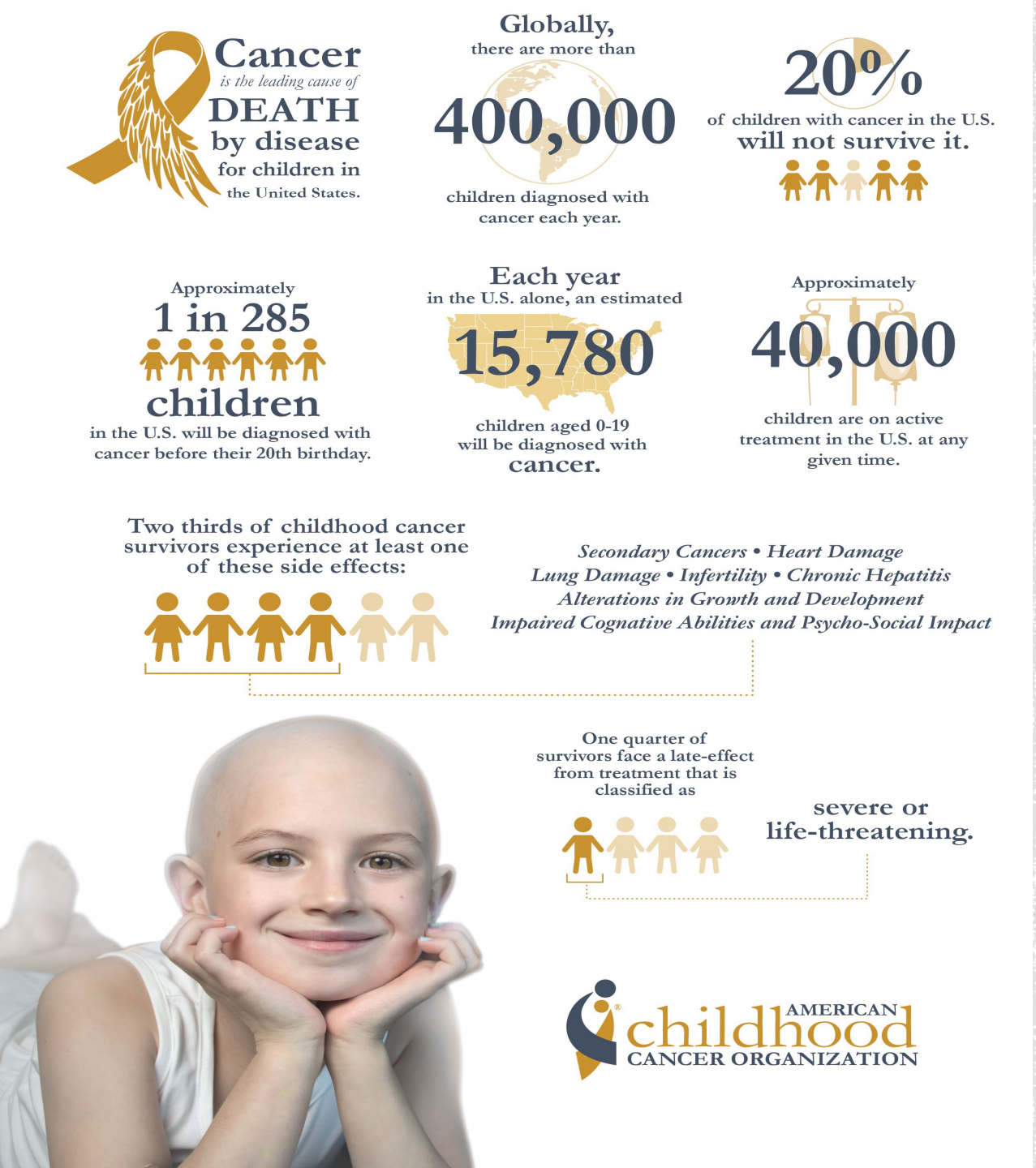
MONDAY'S AT HASBRO

FROM CROWN TO CAP



PALLIATIVE CARE

The World Health Organization defines palliative care as a comprehensive care approach which "improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."



SURVIVORS NEED CARE TOO

- 400,000 pediatric cancer survivors in the U.S., an estimated 73 percent will have a chronic health condition. Studies suggest 42 percent of those will likely experience a severe, disabling or life-threatening condition or death.
- Modifications in treatment are reducing exposures to radiotherapy and chemotherapy.

73% WILL HAVE A CHRONIC HEALTH CONDITION

The early integration of palliative care as a standard across sites and settings provides meaningful opportunity to care for not only the physical domains impacted by cancer, but to also attend to the full impact of illness on the patient's psychological, developmental, and spiritual wellness within the social context of each patient's family and community.

TRUE OR FALSE

Palliative care is currently a used practice in all pediatric care settings?

Let us never consider ourselves finished, nurses. We must be learning all of our lives.

Florence Nightingale, *founder of modern nursing*

Any Questions?

THANK YOU!

REFERENCES

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- Siegel, D. A., Richardson, L. C., Henley, S. J., Wilson, R. J., Dowling, N. F., Weir, H. K., . . . Lunsford, N. B. (2020). Pediatric cancer mortality and survival in the United States, 2001-2016. *Cancer, 126*(19), 4379-4389. doi:10.1002/cncr.33080

Pediatric, Adolescent and Young Adult (PYAC) Cancer Reporting and Survivors' Long-term Hardship

A Decade of Promise in Pediatric Cancer and Palliative Care: Survivorship in 2021

Annual Cancer Summit: November 4, 2021

Partnership to Reduce Cancer in Rhode Island

Disclosures

- No relevant conflicts of interest nor financial disclosures

Agenda

- Cancer Registry
- Data Collection
- Special Projects

RICR supported by State of Rhode Island, and CDC National Program of Cancer Registries (NPCR: NU58DP006291)

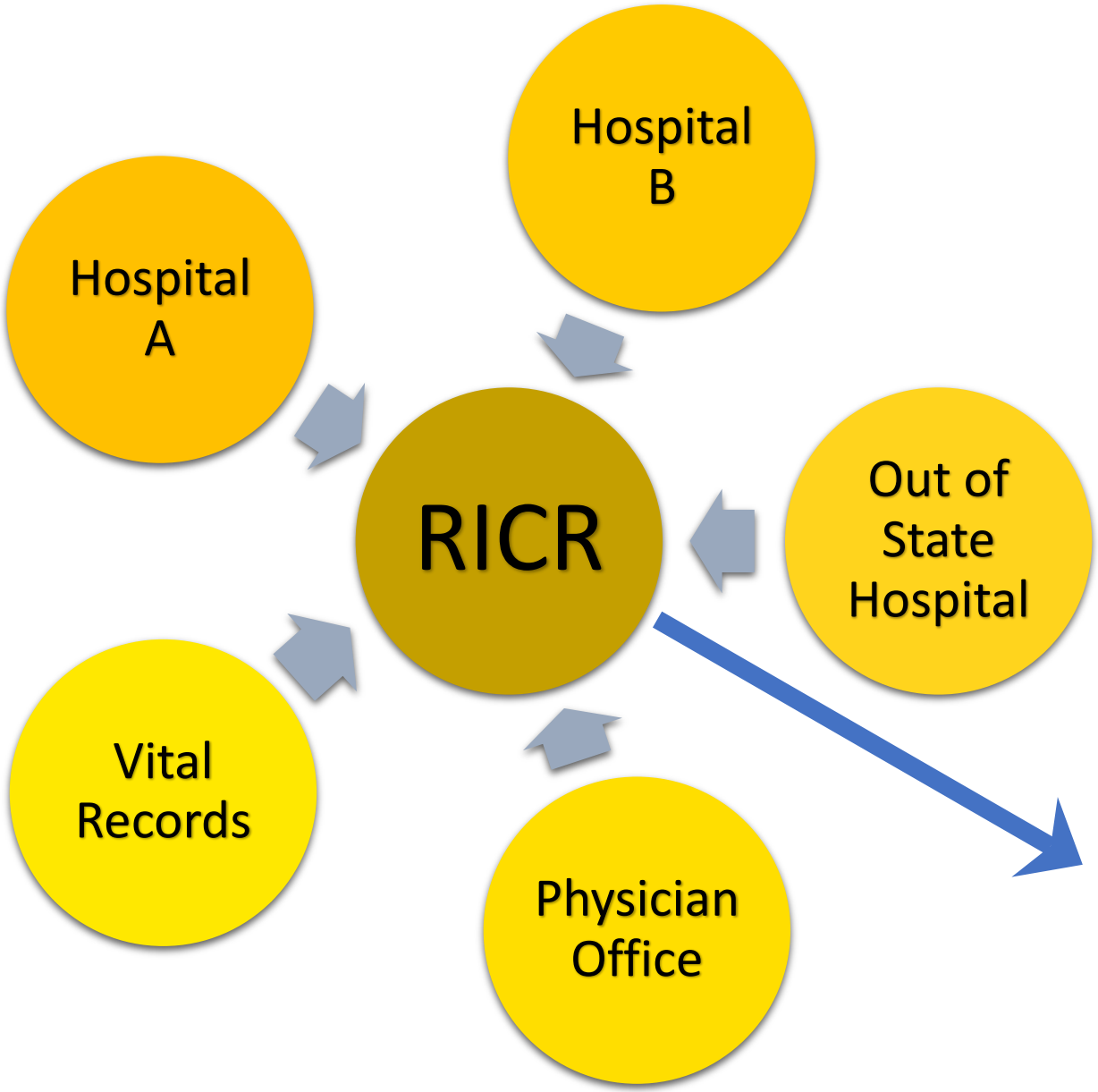
Rhode Island Cancer Registry (RICR)

Data Repository

Who	How	What	When	Why
• Cancers diagnosed and/or treated in RI since 1986 • RI residents (all ages) diagnosed and/or treated outside of RI	• Hospitals and radiation centers in RI • Agreements with other Central Registries all over the US	• Demographic information • Tumor specific information • Treatment • Vital record	• Within 6 months of diagnosis date or date of first contact • Regulations changed to 30-45 days of diagnosis date or date of first contact	• Produce comprehensive epidemiological reports on cancer • Prepare and publish extensive technical and statistical reports and publications • Support public health policy/programs

Data Collection

Putting the puzzle together



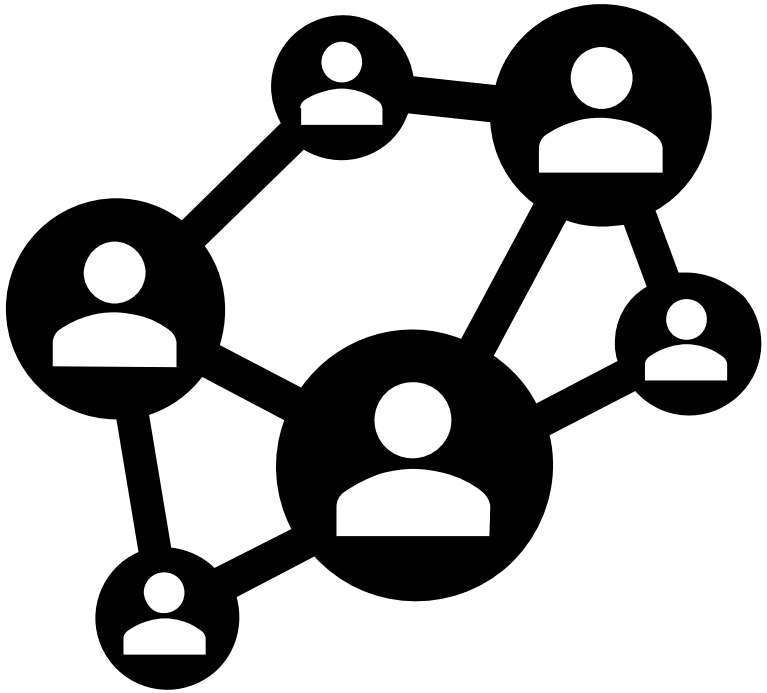
- Diagnosis at Hospital A
- Bloodwork at Physician Office
- 2nd opinion and further workup at Out of State Hospital
- Surgery at Hospital B
- Chemotherapy at Hospital B

CDC

CENTERS FOR DISEASE CONTROL AND PREVENTION

Special Projects

Previous and Current



Caroline Pryce Walker Conquer Childhood Cancer Act of 2008

- Senator Norm Coleman (R-MN) and Representative Deborah Pryce (R-OH), whose adopted daughter, Caroline Pryce Walker, died of neuroblastoma, introduced this legislation in 2008 to authorize funds to raise awareness about childhood cancer and support children who are suffering from this disease and their families.
- Enhance, expand, and intensify pediatric cancer research and other activities related to pediatric cancer
  - Therapeutically applicable research to generate effective treatments
  - Pediatric preclinical testing
  - Pediatric clinical trials
- Senator Reed of Rhode Island sponsored the re-authorization to expand and improve the federal efforts in 2013.

H.R.1553 - Caroline Pryce Walker Conquer Childhood Cancer Act of 2008

https://www.congress.gov/bill/110th-congress/house-bill/1553

Early Case Capture of Pediatric and Young Adult Cancers (ECC/PYAC)

- Pilot Enhancement Study
  - Participated since 2014; ages 000-019
  - Continued under STAR Act
- Previous & Current
  - Accessibility by researchers and Incidence and Prevalence: 24-36 months post diagnosis
- Develop methods for rapid cancer reporting
  - Increase availability of data to researchers and providers
- Decrease reportability timeliness to 30 days post diagnosis
- Success during project timeframe

Childhood Cancer STAR Act

Sponsored by Sen. Jack Reed in RI; Law June 5, 2018

Survivorship, Treatment, Access, and Research Act

- Timely collection
- Electronic cancer reporting
- Disease research and treatment

Maximizing research through discovery

Maximizing delivery

- Care
- Quality of life
- Survivorship
- Caregiver support

RICR Participation began in 2020

Ages 000-029

RICR and Hasbro Children's Hospital

- Incorporate NOAH tool
- Pathology reports sent directly and electronically

All facility engagement

- Suspense files monthly

Similar outcome from the ECC/PYAC project

- Decrease reporting timeline to 30 days post diagnosis

Rapid Case Ascertainment to continue in future

S.292 - Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2018
https://www.congress.gov/bill/115th-congress/senate-bill/292

Questions?

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Pediatric, Adolescent & Young Adult (PAYA) Cancer Reporting; Survivors' Long-term Hardship

November 4, 2021

Partnership to Reduce Cancer in Rhode Island

Cancer Summit

Disclosure

- RICR supported by State of Rhode Island, and CDC National Program of Cancer Registries (NPCR: NU58DP006291)

- I have no relevant conflicts of interest nor financial disclosures to report.

Overview

- ✓**P**ediatric cancer classification
- ✓**A**dolescent and **Y**oung **A**dult cancer classification
- ✓Overview of PAYA cancer epidemiology in RI:

  Incidence, trend, cancer profile by age, sex & year
- ✓ Long-term and late effects (literature reviews)

P-AYA Cancer Classifications

- Different from cancers of adults age ≥ 40 years (by anatomical sites: breast, prostate, lung, etc.)[1]
- Reflecting distinctive cancer sites & biology
  - ✓ Pediatric (0-14 yrs): 12 main & 47 extended groups[2]
  - ✓ AYA (15-39 yrs): 12 main & 77 extended groups[3]
- Useful in population-based epidemiological studies

1. SEER Site Recode ICD-O-3/WHO 2008 Definition. Site Recode ICD-O-3/WHO 2008 - SEER Data Reporting Tools (cancer.gov)
2. International Classification of Childhood Cancer (ICCC). ICCC Recode Third Edition ICD-O-3/IARC 2017 Table - SEER Recodes (cancer.gov)
3. SEER Adolescent and Young Adult (AYA) Site Recode 2020 Revision. AYA Site Recode 2020 Revision - SEER Recodes (cancer.gov)

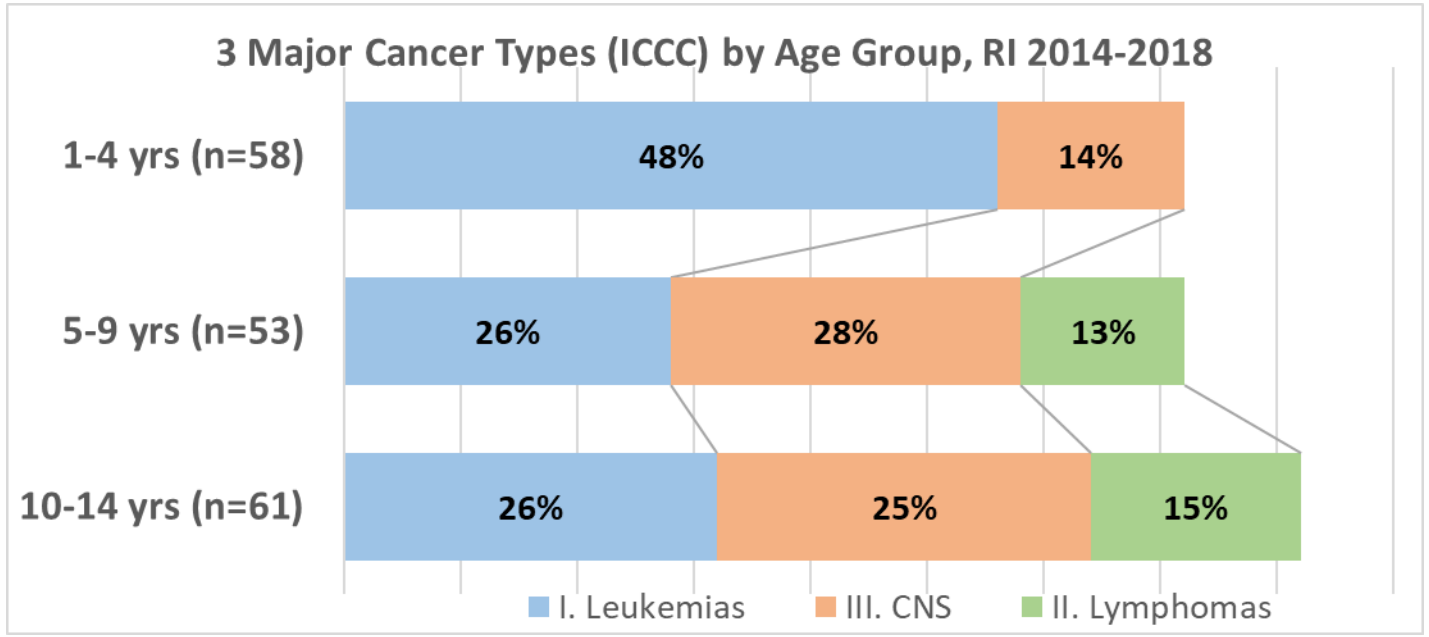
P-AYA Cancer Classifications

Highlighted are common types

Pediatric (0-14 years) by ICCC	Adolescent & Young Adult (AYA: 15-39 year)
I. Leukemia → ALL, AML, CML, etc.	1. Leukemia → ALL, AML, CML, CLL, etc.
II. Lymphoma → Hodgkin, Non-Hodgkin, Burkitt, etc.	2. Lymphoma → NHL, HL, Myelomas, etc.
III. CNS & intracranial/intraspinal	3. CNS & intracranial/intraspinal
IV. Neuroblastoma & peripheral nervous	4. Sarcoma → bone & soft tissues
V. Retinoblastoma	5. Blood & lymphatic vessel tumor
VI. Renal tumor	6. Nerve sheath tumor
VII. Hepatic tumor	7. Germ cell/non germ cell gonadal (testis, ovary, etc)
VIII. Bone sarcoma → osteo-, chondro-, Ewing, etc.	8. Malignant melanoma
IX. Soft tissue sarcoma → Rhabdomyo-, firbro-, Kaposi, etc.	9. Carcinoma → by anatomical site
X. Germ cell, trophoblastic & gonadal	10. Miscellaneous specified
XI. Other carcinoma & melanoma	11. Unspecified malignant
XII. Other & unspecified malignant	12. In situ → by anatomical site

Pediatric Cancer Overview

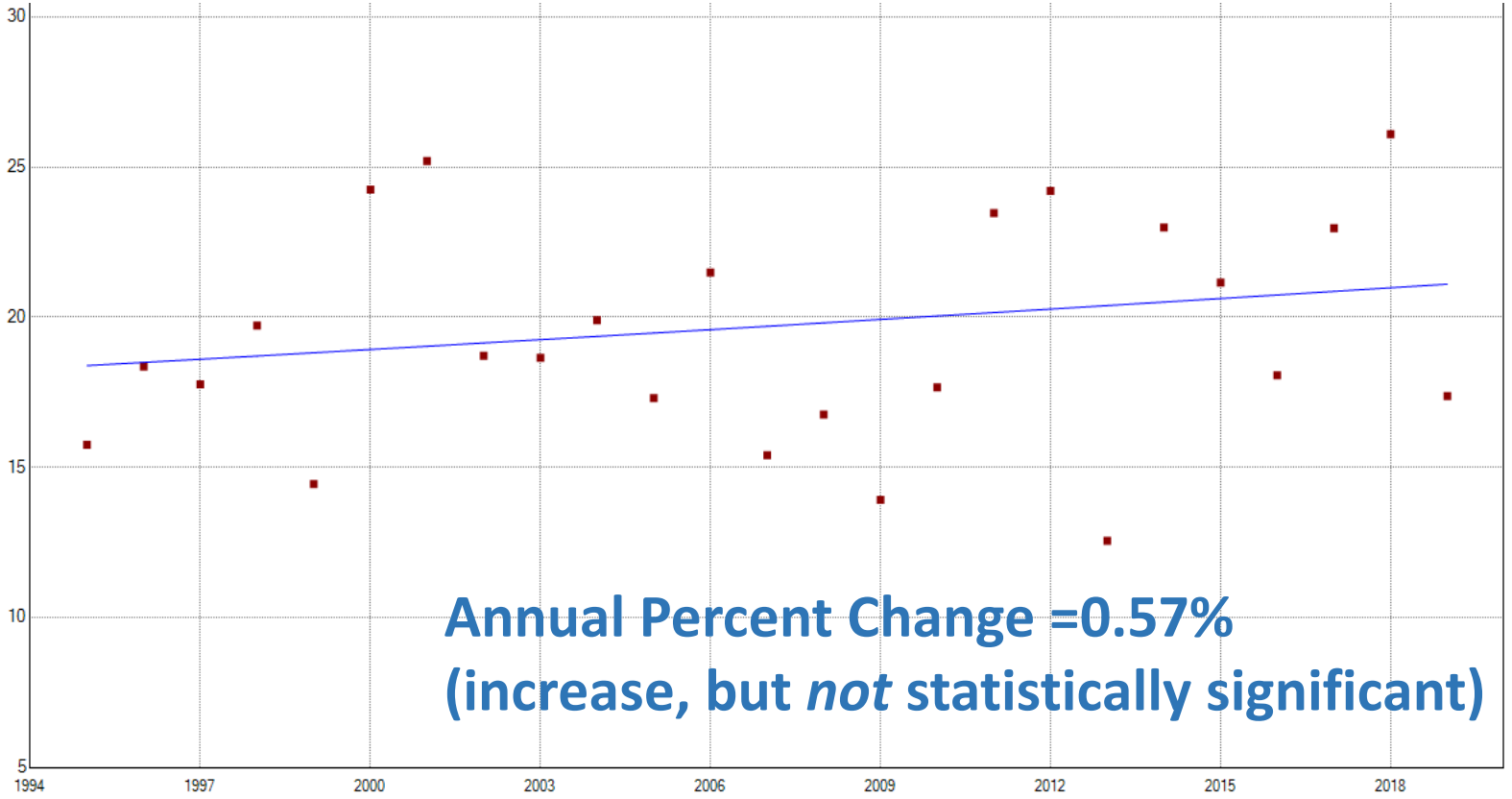
- ✓US 2020: 11,000 children (0-14 yrs) & 1,200 deaths[4]
- ✓RI 2014-2018: 40 cases/yr = 22/100,000 children[5]
- ✓Cancer type varied by children's age



4. ACS Cancer Facts and Figures, 2020. American Cancer Society; 2020. Cancer Facts & Figures 2020
5. Rhode Island Cancer Registry

Pediatric Cancer Trend, Age 0-14
RI 1995-2019

Age-adjusted rate
/100,000 children*

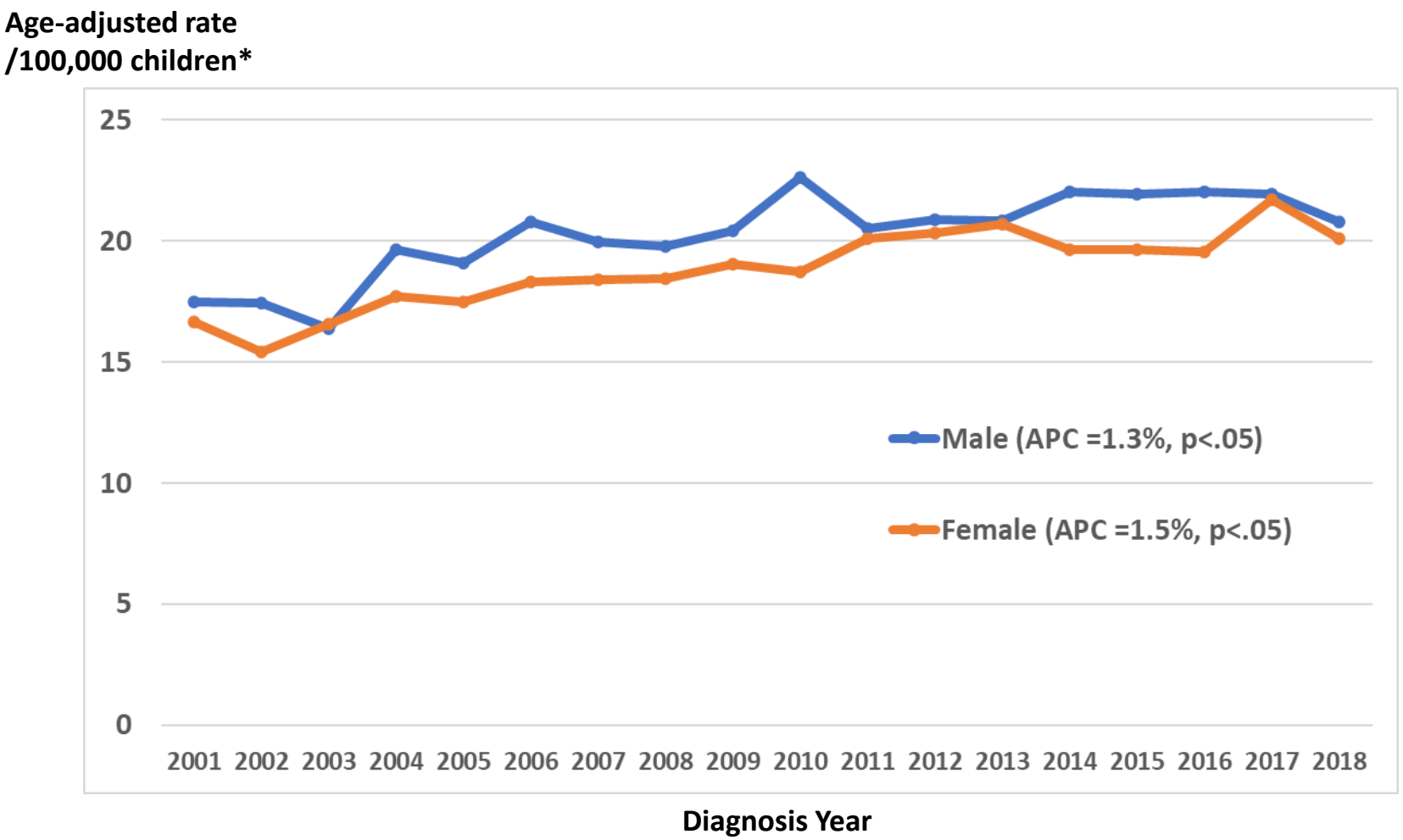


Diagnosis Year

* Age-adjusted to US 2000 standardized population

Source: Rhode Island Cancer Registry (as of September 2021), analyzed using Jointpoint Regression Program v4.8.0.1, Statistical Research and Applications Branch, NIH

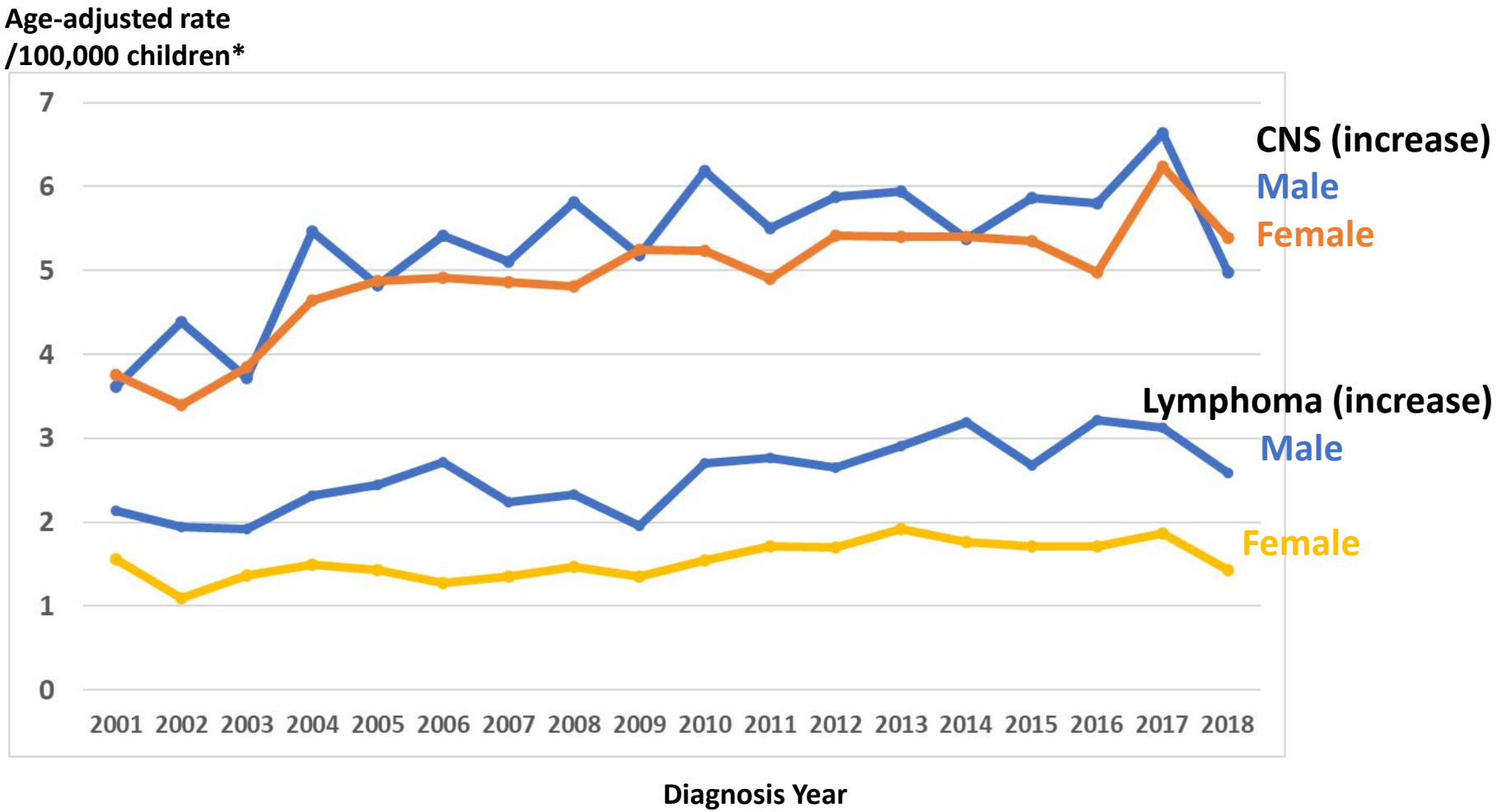
Pediatric Cancer Trend, Age 0-14
US Northeast 2001-2018



* Age-adjusted to US 2000 standardized population

Source: US Caner Statics Public Use Database (November 2020), analyzed using SEER Stat 8.3.9, NCI

Pediatric Cancer Trend by Major Site, Age 0-14
US Northeast 2001-2018



* Age-adjusted to US 2000 standardized population

Source: US Caner Statics Public Use Database (November 2020), analyzed using SEER Stat 8.3.9, NCI

AYA (15-19 years) Cancer Overview

✓US 2020[4] :

Table S1. Estimated Cancer Cases and Deaths in AYAs by Age, US, 2020

Age	Estimated cases	Estimated deaths
15-19 years	5,800	540
20-29 years	24,900	2,210
30-39 years	58,800	6,520
Total	89,500	9,270

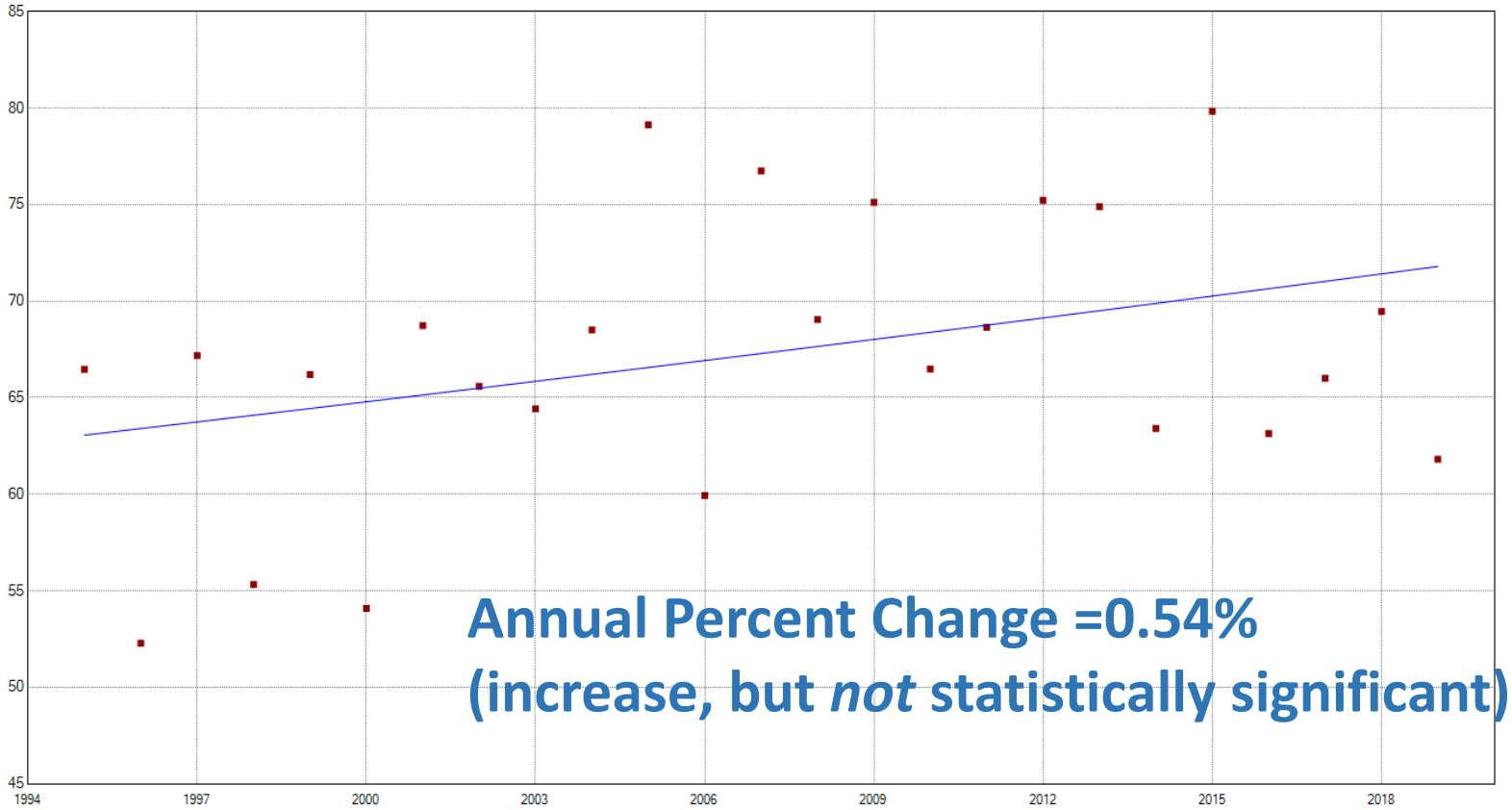
✓RI 2014-2018: ~400 cases/year = 115/100,000 AYA[5]

- 5% of all RI cancer case reporting
- Female: 271 cases/year = 163 per 100,000
- Male: 106 cases/year = 68 per 100,000

4. ACS Cancer Facts and Figures, 2020. American Cancer Society; 2020. Cancer Facts & Figures 2020
5. Rhode Island Cancer Registry

AYA Cancer Trend, **Male** Age 15-39
RI 1995-2019

Age-adjusted rate
/100,000 AYA*

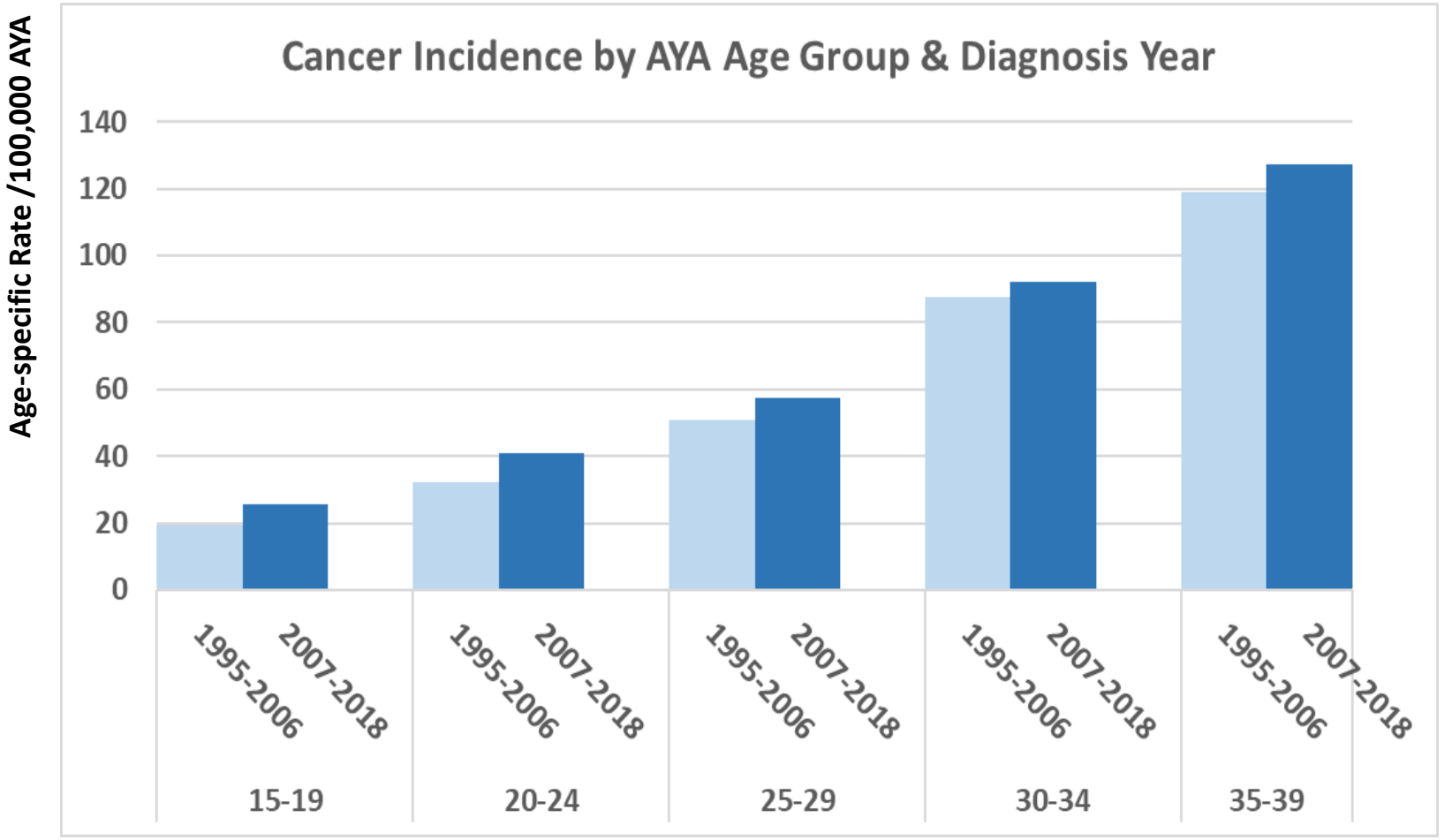


Diagnosis Year

* Age-adjusted to US 2000 standardized population

Source: Rhode Island Cancer Registry (as of September 2021), analyzed using Jointpoint Regression Program v4.8.0.1, Statistical Research and Applications Branch, NIH

AYA Cancer Trend, **Male** Age 15-39
RI 1995-2019



Source: Rhode Island Cancer Registry (as of September 2021)

AYA Cancer Trend by Site, **Male Age 15-19** US 1995-2019

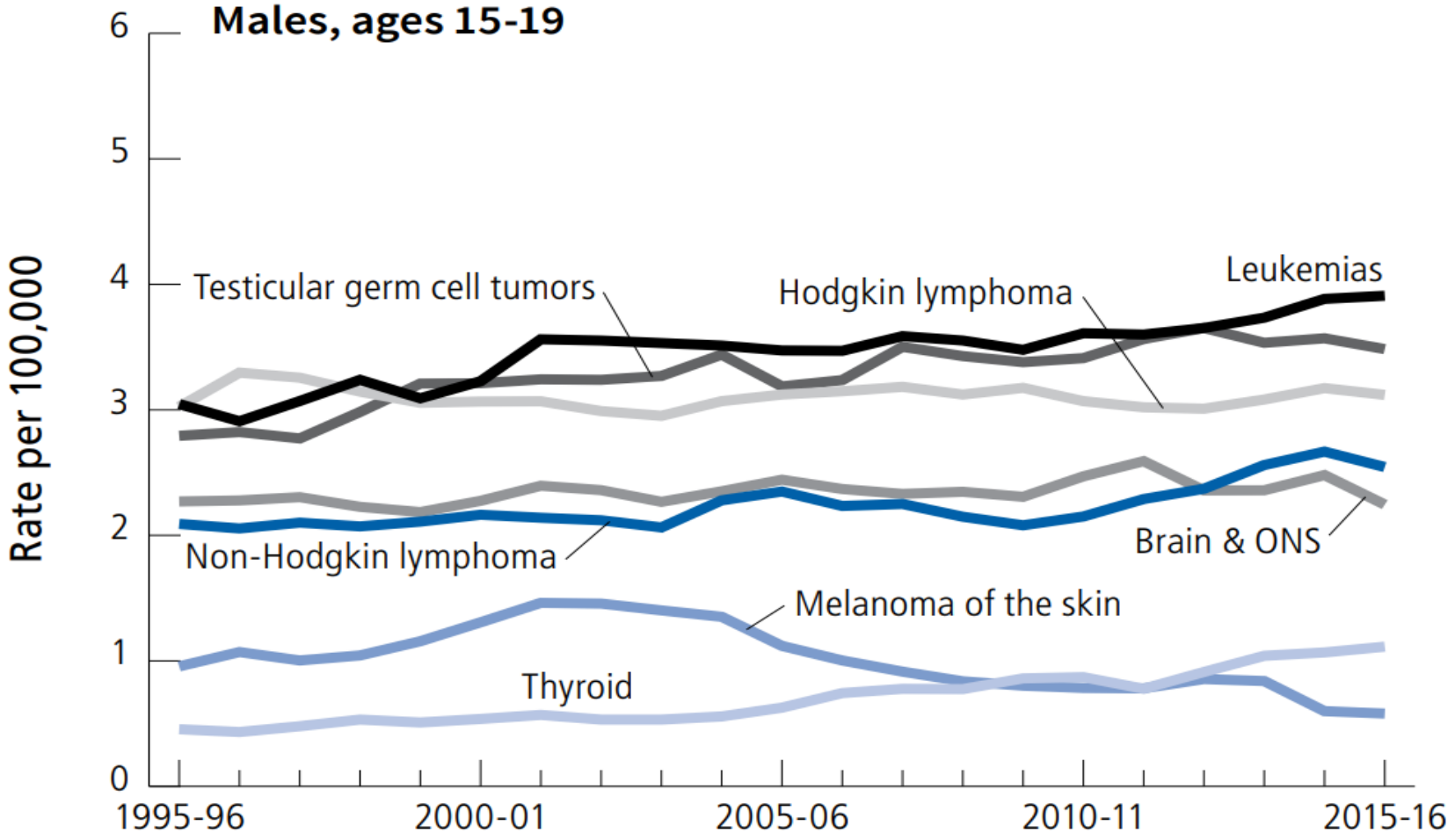
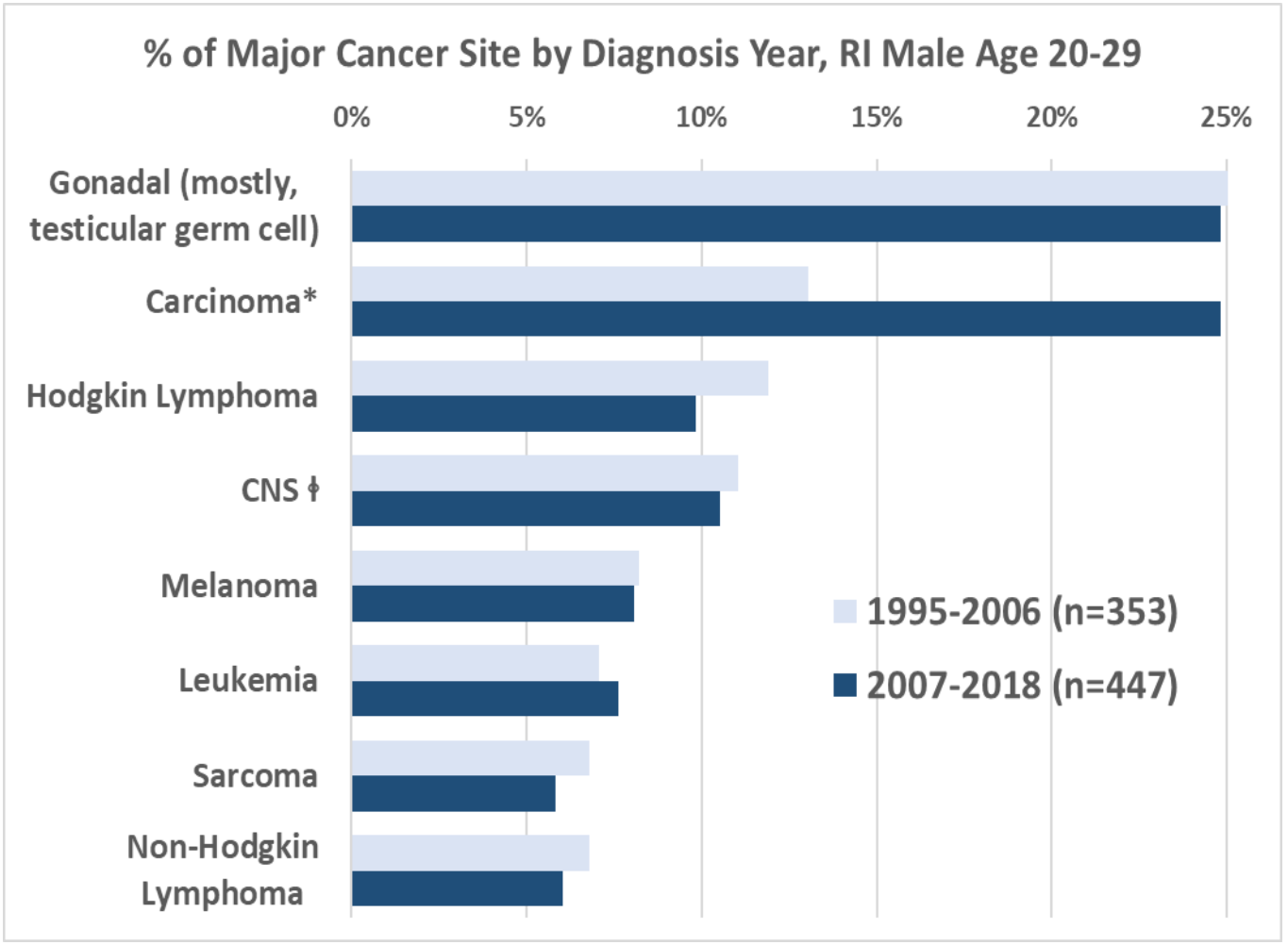


Figure source: ACS Cancer Facts and Figures, 2020. American Cancer Society; 2020. Special Section: Cancer in Adolescents and Young Adults. [Cancer Facts & Figures 2020]

AYA Cancer Trend by Site, **Male Age 20-29** RI 1995-2019

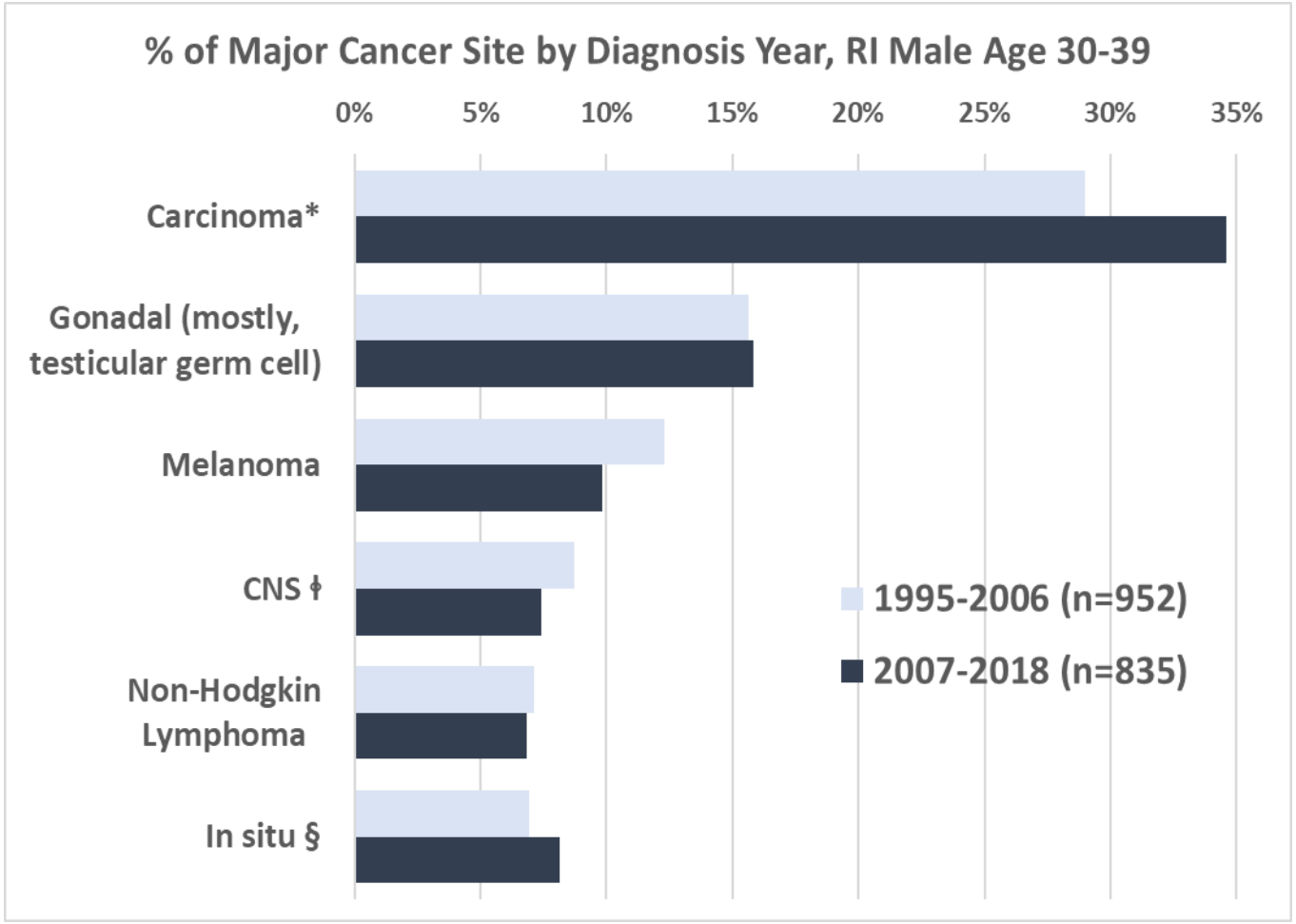


Source: Rhode Island Cancer Registry (as of September 2021)

* Of all anatomical sites, excluding skin melanoma; behavior code 3 (invasive malignant)

† includes behavior codes 0 (benign) and 1 (borderline) tumors

AYA Cancer Trend by Site, **Male Age 30-39** RI 1995-2019



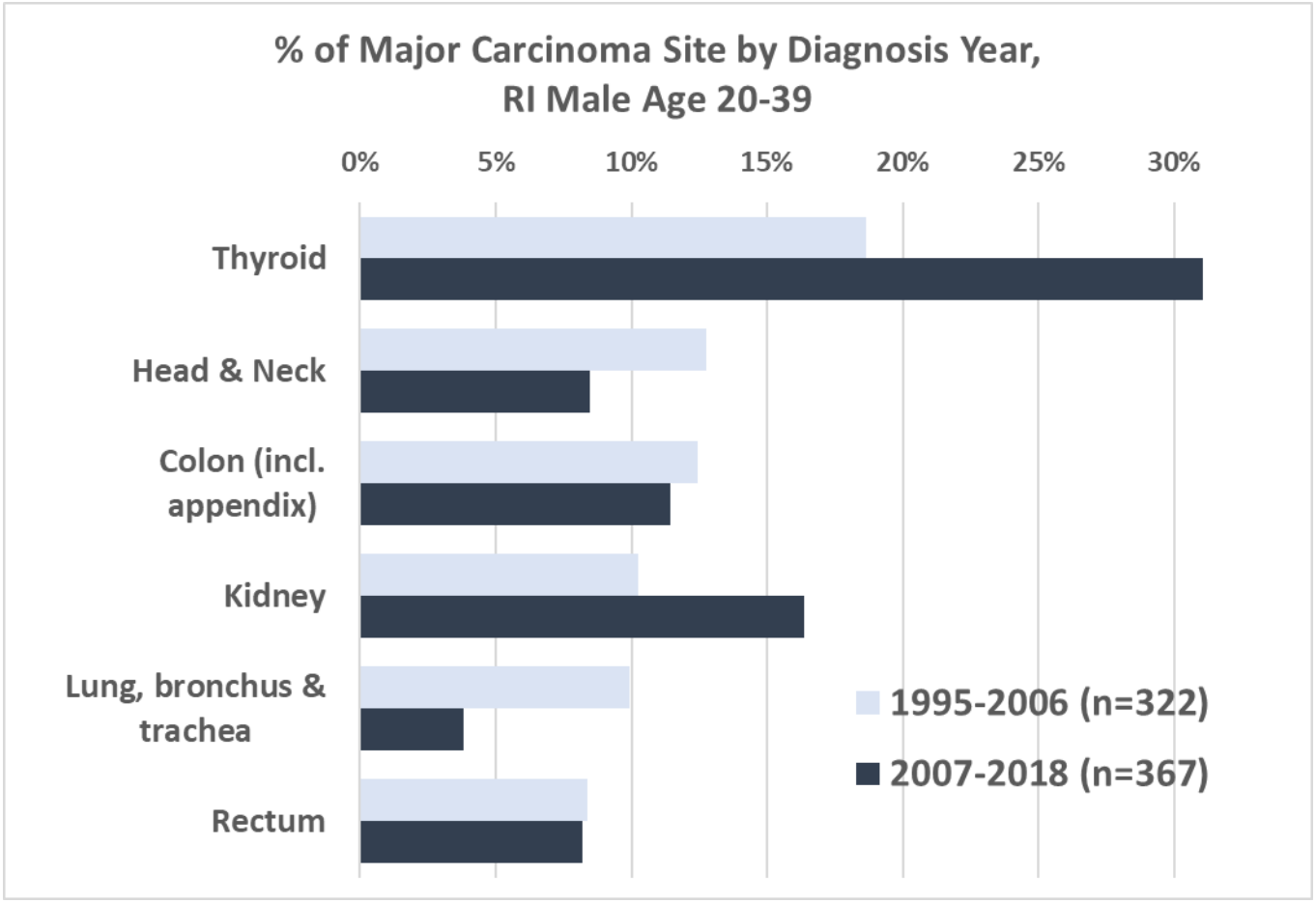
Source: Rhode Island Cancer Registry (as of September 2021)

* Of all anatomical sites, excluding skin melanoma; behavior code 3 (invasive malignant)

ǂ includes behavior codes 0 (benign) and 1 (borderline) tumors

§ Of all anatomical sites; behavior code 2 (in situ); PIN III (prostate in situ) not collected by RICR

Carcinomas by Sites*, **Male Age 20-39** RI 1995-2019

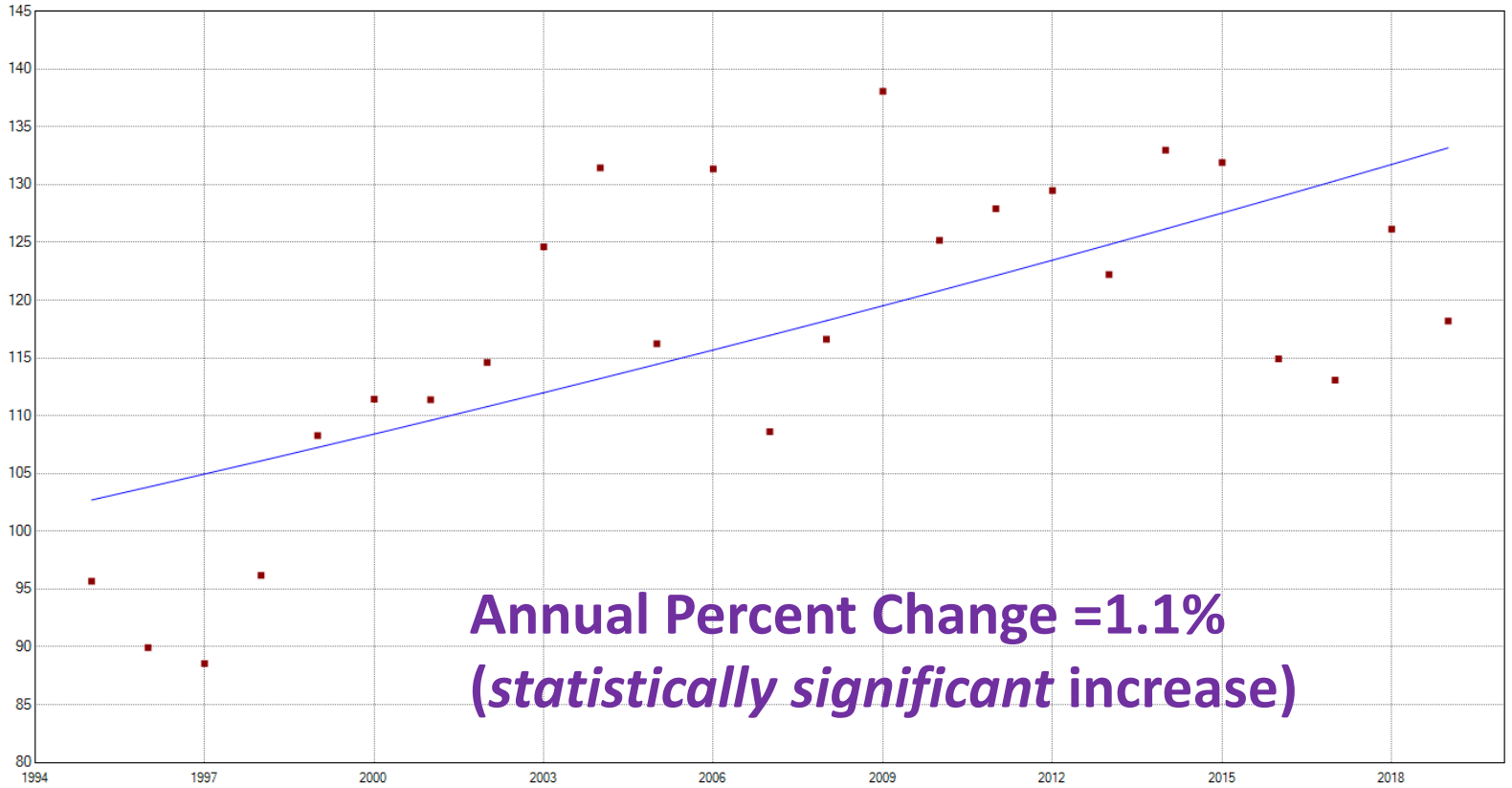


Source: Rhode Island Cancer Registry (as of September 2021)

* Of all anatomical sites, excluding skin melanoma; behavior code 3 (invasive malignant)

AYA Cancer Trend, **Female** Age 15-39
RI 1995-2019

Age-adjusted rate
/100,000 AYA*

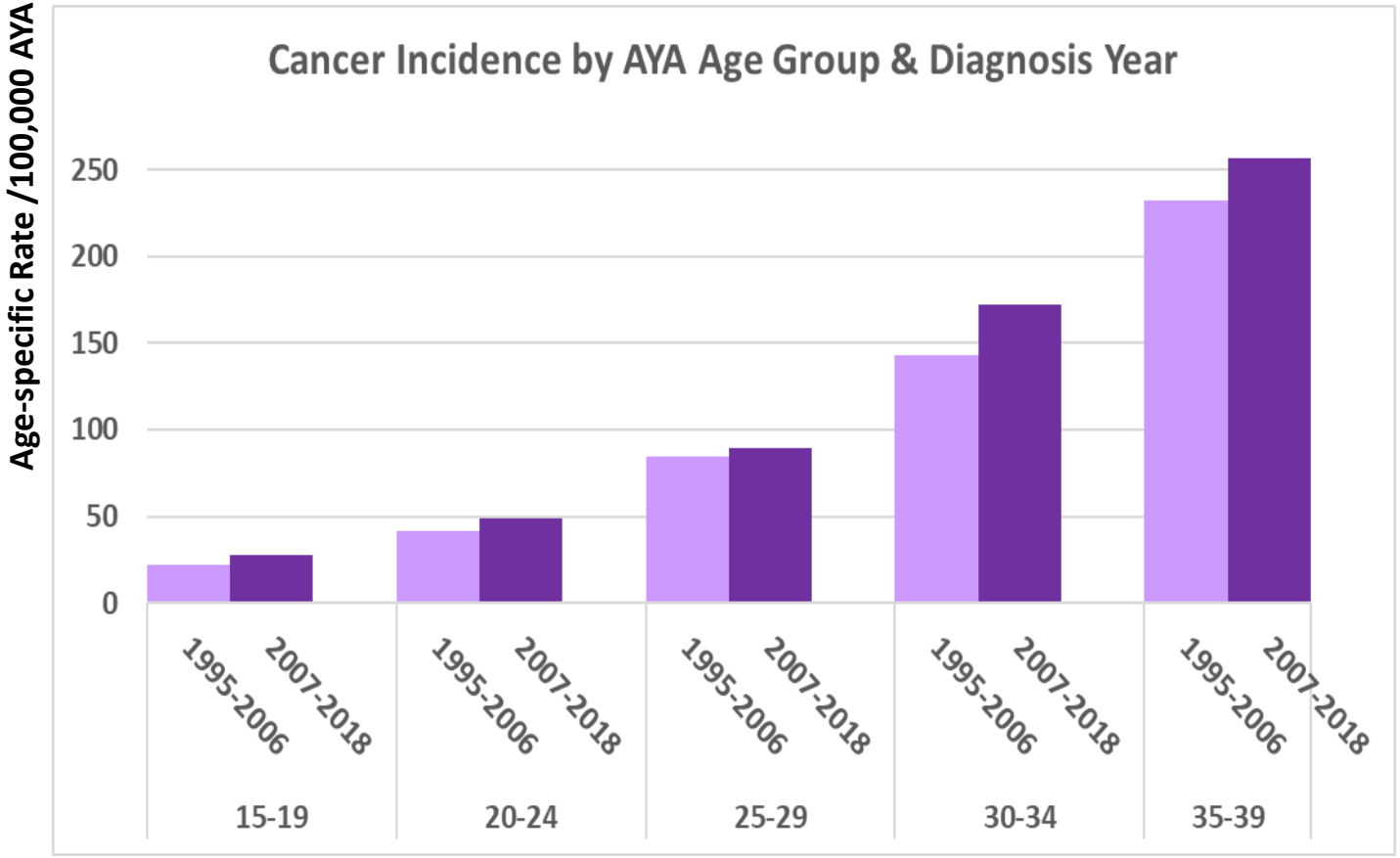


Diagnosis Year

* Age-adjusted to US 2000 standardized population

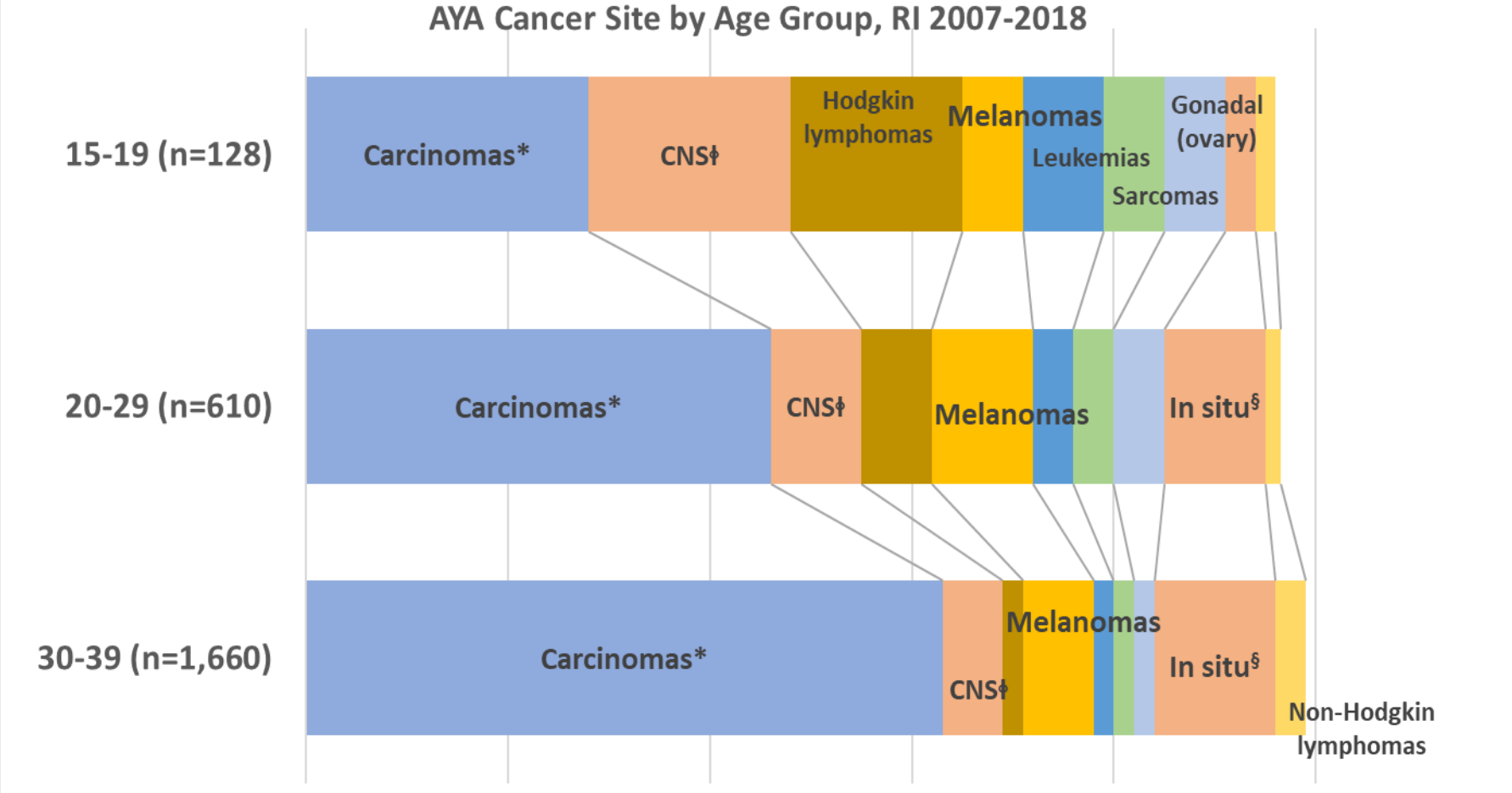
Source: Rhode Island Cancer Registry (as of September 2021), analyzed using Jointpoint Regression Program v4.8.0.1, Statistical Research and Applications Branch, NIH

AYA Cancer Trend, **Female** Age 15-39
RI 1995-2019



Source: Rhode Island Cancer Registry (as of September 2021)

Cancer Site by Age, **Female** Age 15-39
RI 2007-2018



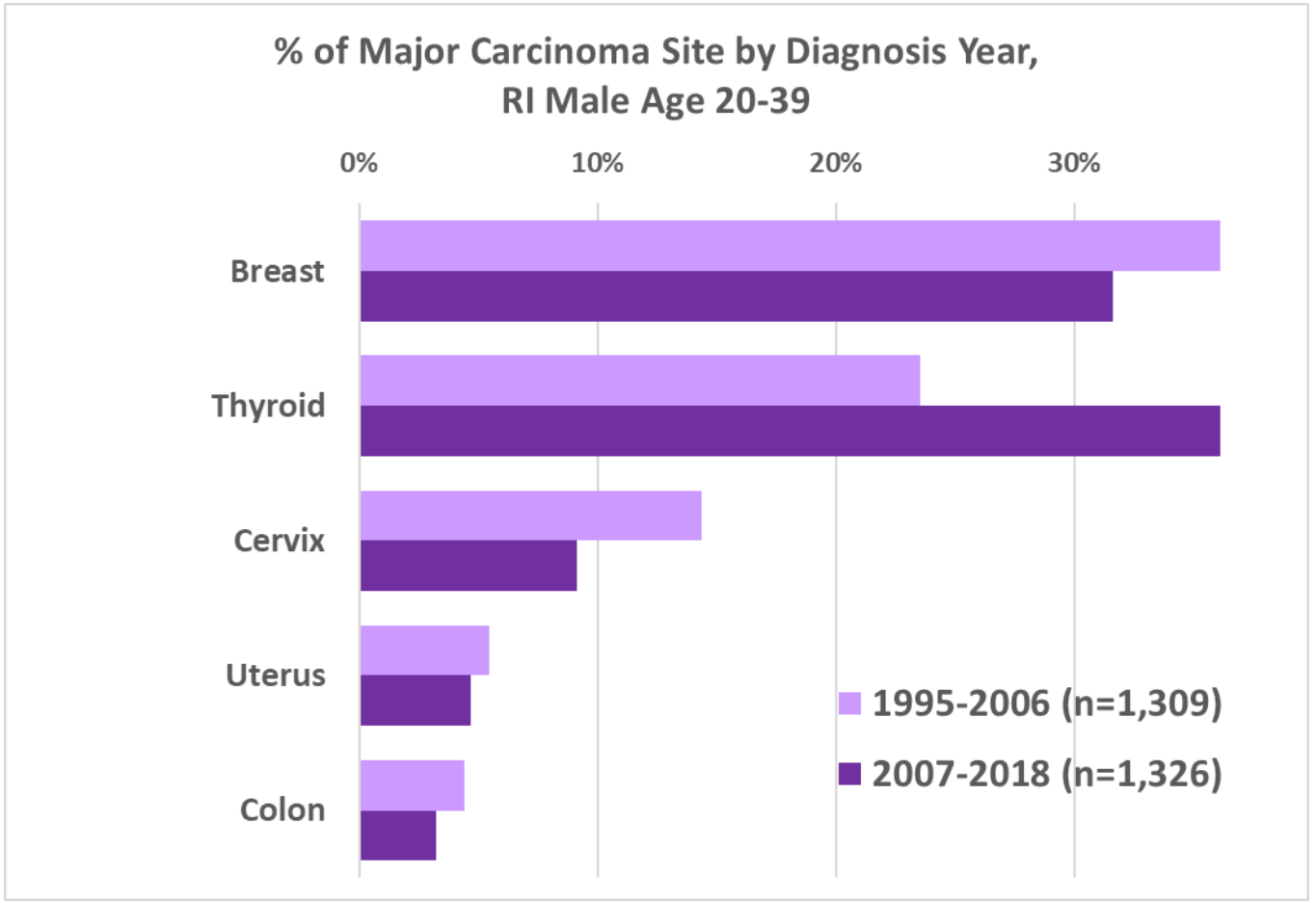
Source: Rhode Island Cancer Registry (as of September 2021)

* Of all anatomical sites, excluding skin melanoma; behavior code 3 (invasive malignant)

† includes behavior codes 0 (benign) and 1 (borderline) tumors

§ Of all anatomical sites; behavior code 2 (in situ); CIN III and cervical precancer not collected by RICR until 2018

Carcinomas by Sites*, **Female Age 20-39** RI 1995-2019



Source: Rhode Island Cancer Registry (as of September 2021)

* Of all anatomical sites, excluding skin melanoma; behavior code 3 (invasive malignant)

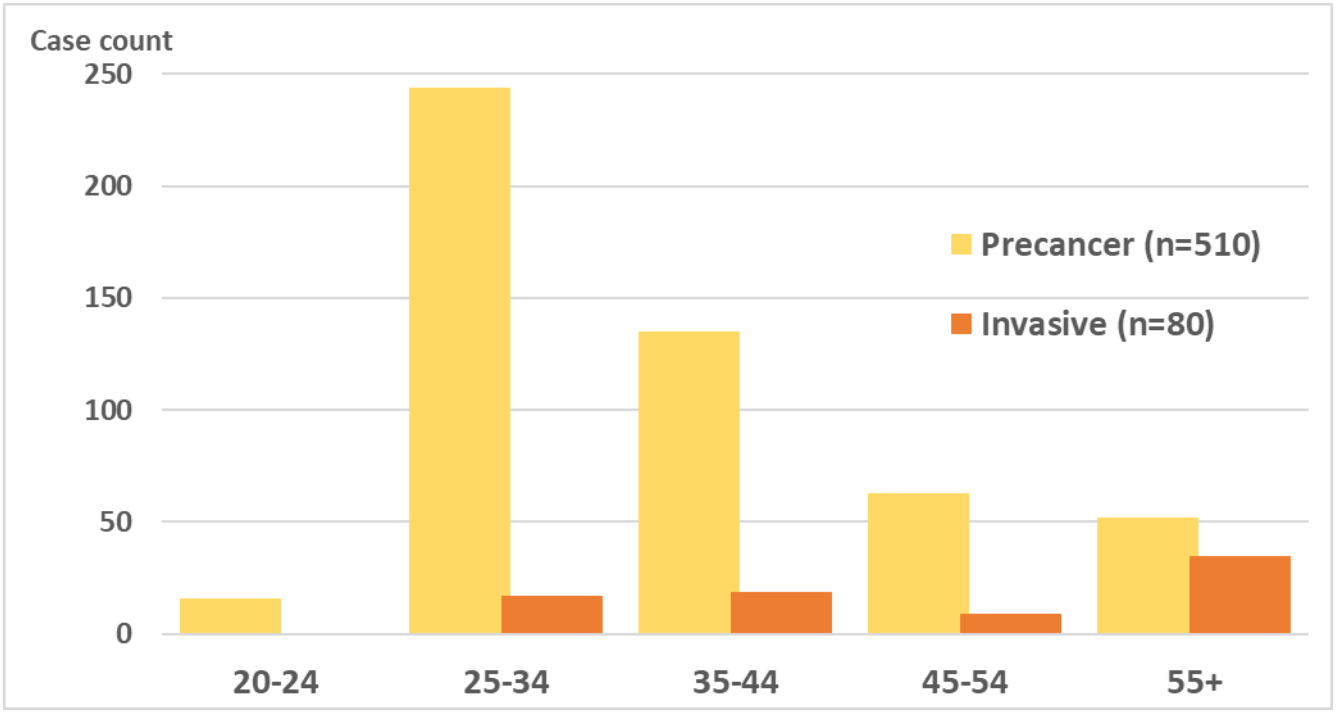
RICR's rule changes of cervical precancer, December 2017

- Revised Regulations* *reinstituted* surveillance of cervical precancer for cases diagnosed in 2018 & forward.
  - ✓intraepithelial neoplasia grade 3 (CIN3)
  - ✓high-grade squamous epithelial lesion (HSIL)
  - ✓carcinoma in situ (CIS)
  - ✓adenocarcinoma in situ (AIS)

* Rhode Island Cancer Registry (216-RICR-10-10-2) - Rhode Island Department of State

Cervical cancer burden, Female age ≥ 20
RI 2018-2019

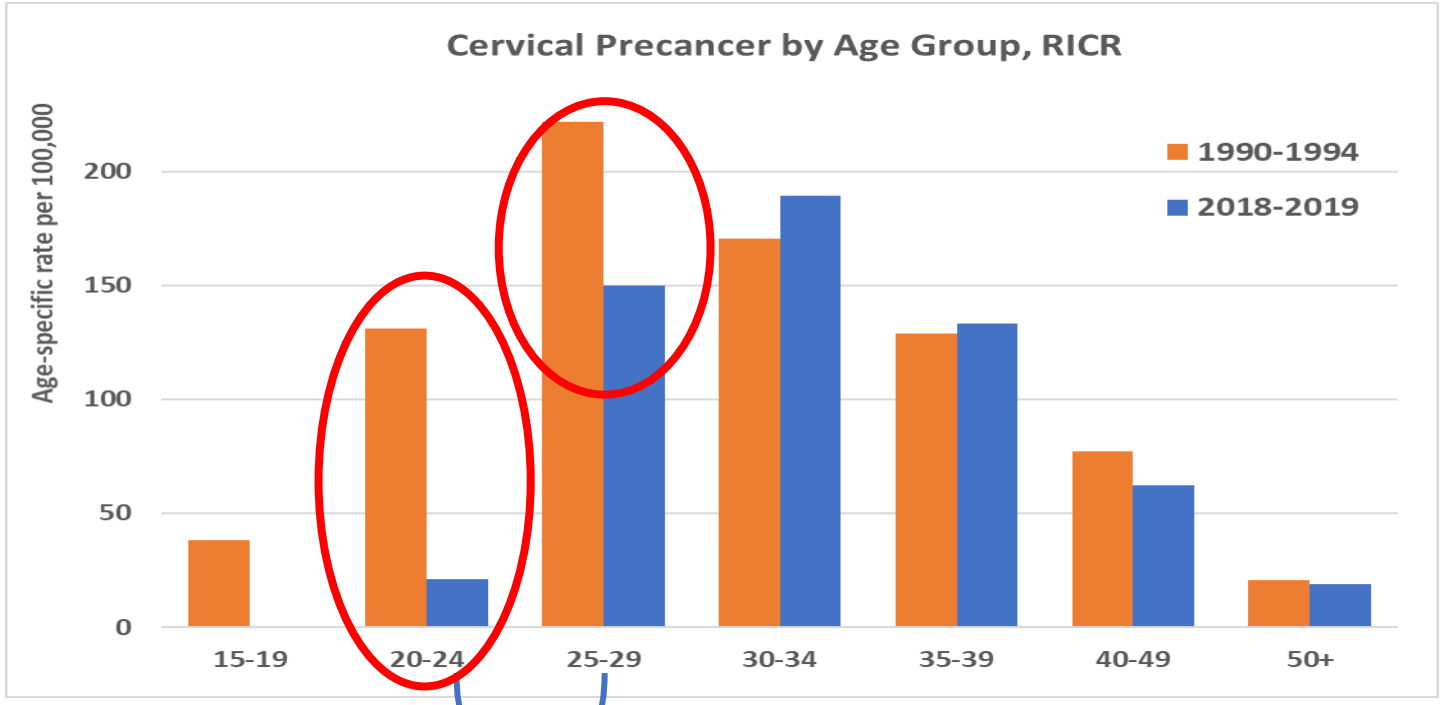
Cervical precancer vs. invasive cancer by women's age at diagnosis, 2018-2019 (total = 590)



Source: Rhode Island Cancer Registry, consolidated reports extracted April 2021

Cervical cancer burden, Female age ≥ 20

Cervical precancer by women's age at diagnosis, 1990-94 vs 2018-19

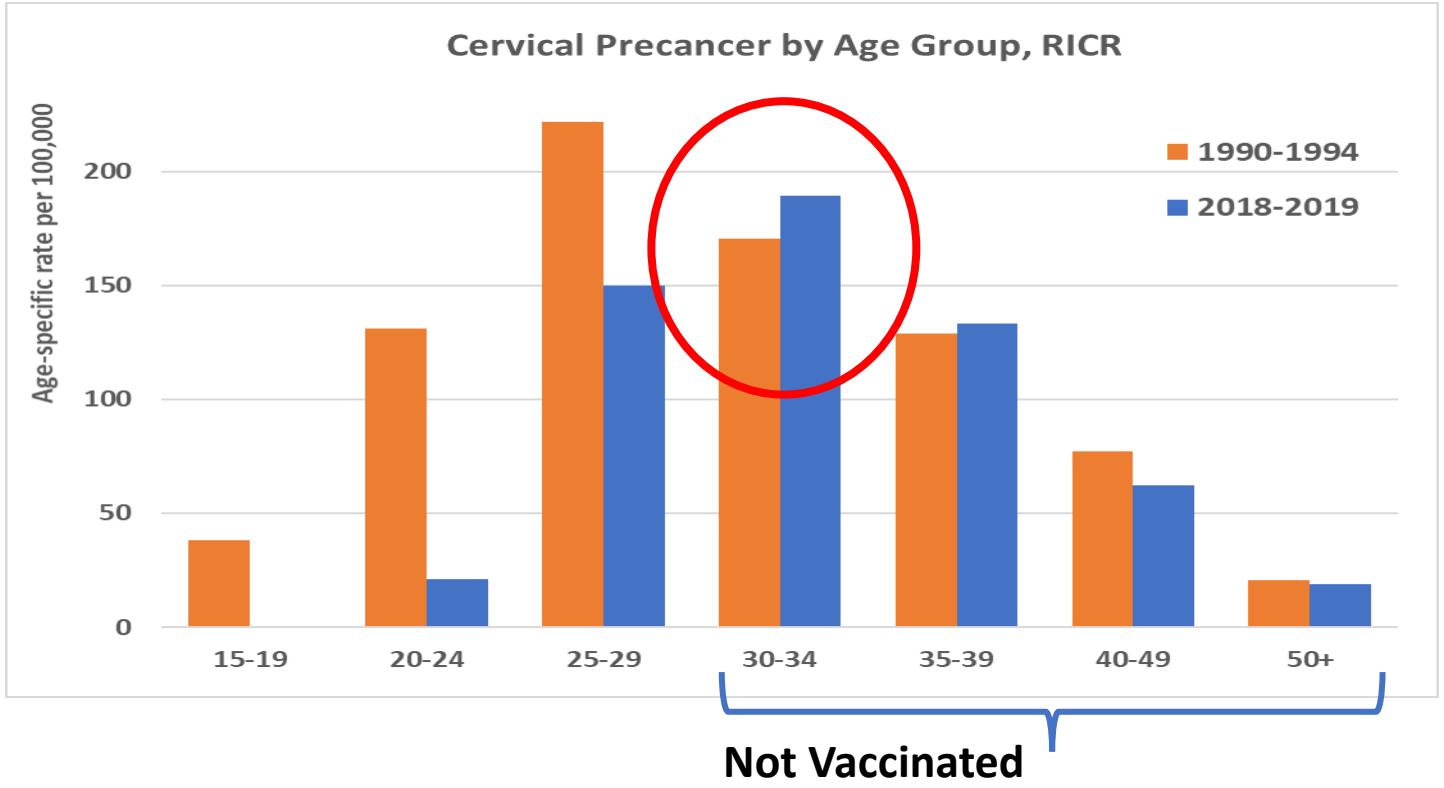


VACCINATED birth cohorts;
Similar screening rate (60%)*

Source: Rhode Island Cancer Registry, consolidated reports extracted April 2021
* RI- All Payor Claim Database.

Cervical cancer burden, Female age ≥ 20

Cervical precancer by women's age at diagnosis, 1990-94 vs 2018-19



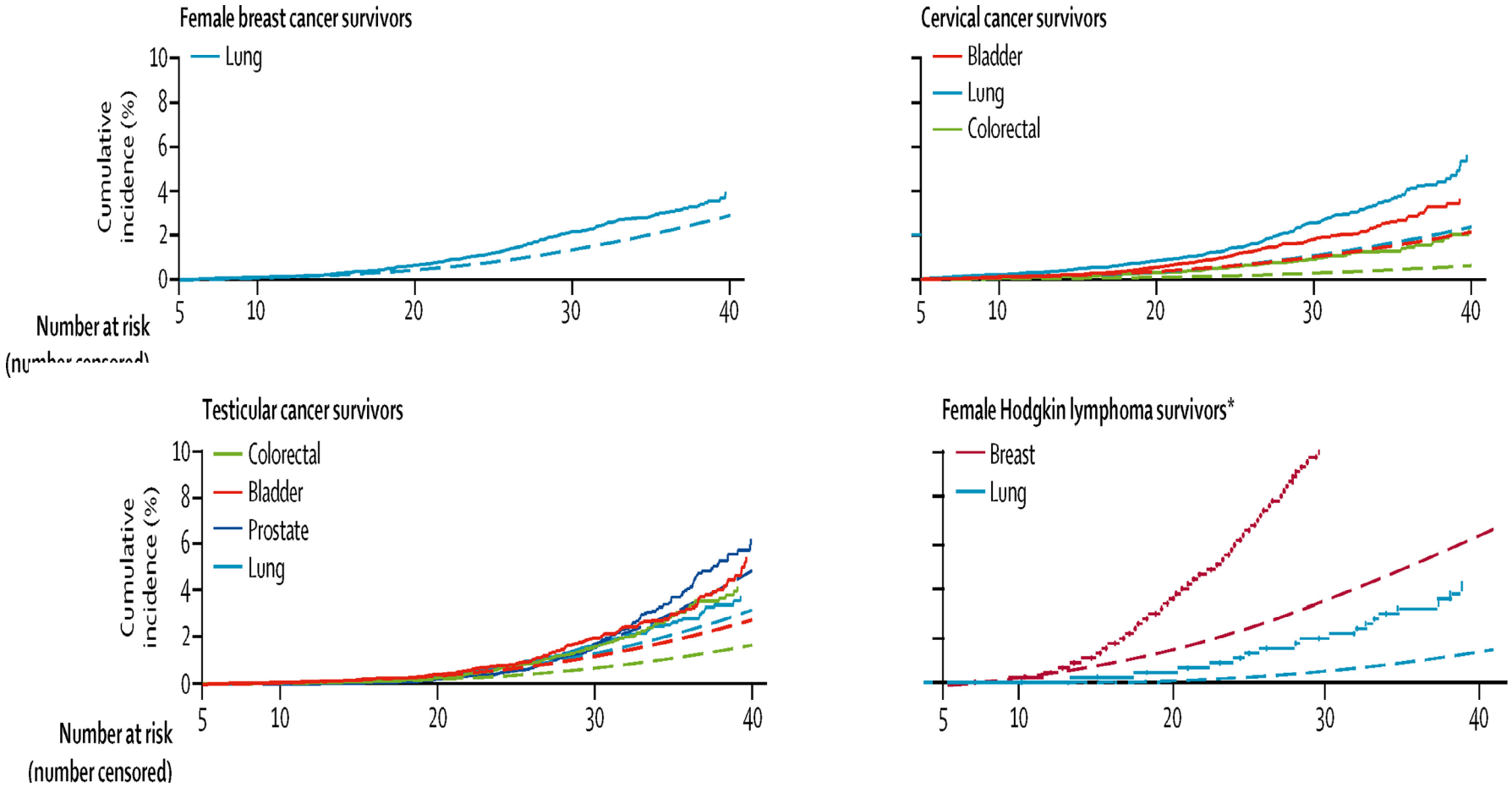
Source: Rhode Island Cancer Registry, consolidated reports extracted April 2021

Long-term and late effects in PAYA cancer survivors [6]

- >80% five-year survival
- “Late Effect”: Health problems develop years after treatment
- Chance of having late effects increases over time
- Tumor, treatment, or patient factor related
- Increased risk of subsequent cancer(s) – myelodysplastic syndrome, solid tumor (breast, thyroid, brain, bone and soft tissue, lung, stomach, liver, colorectal, skin, oral cavity, kidney, bladder etc.)

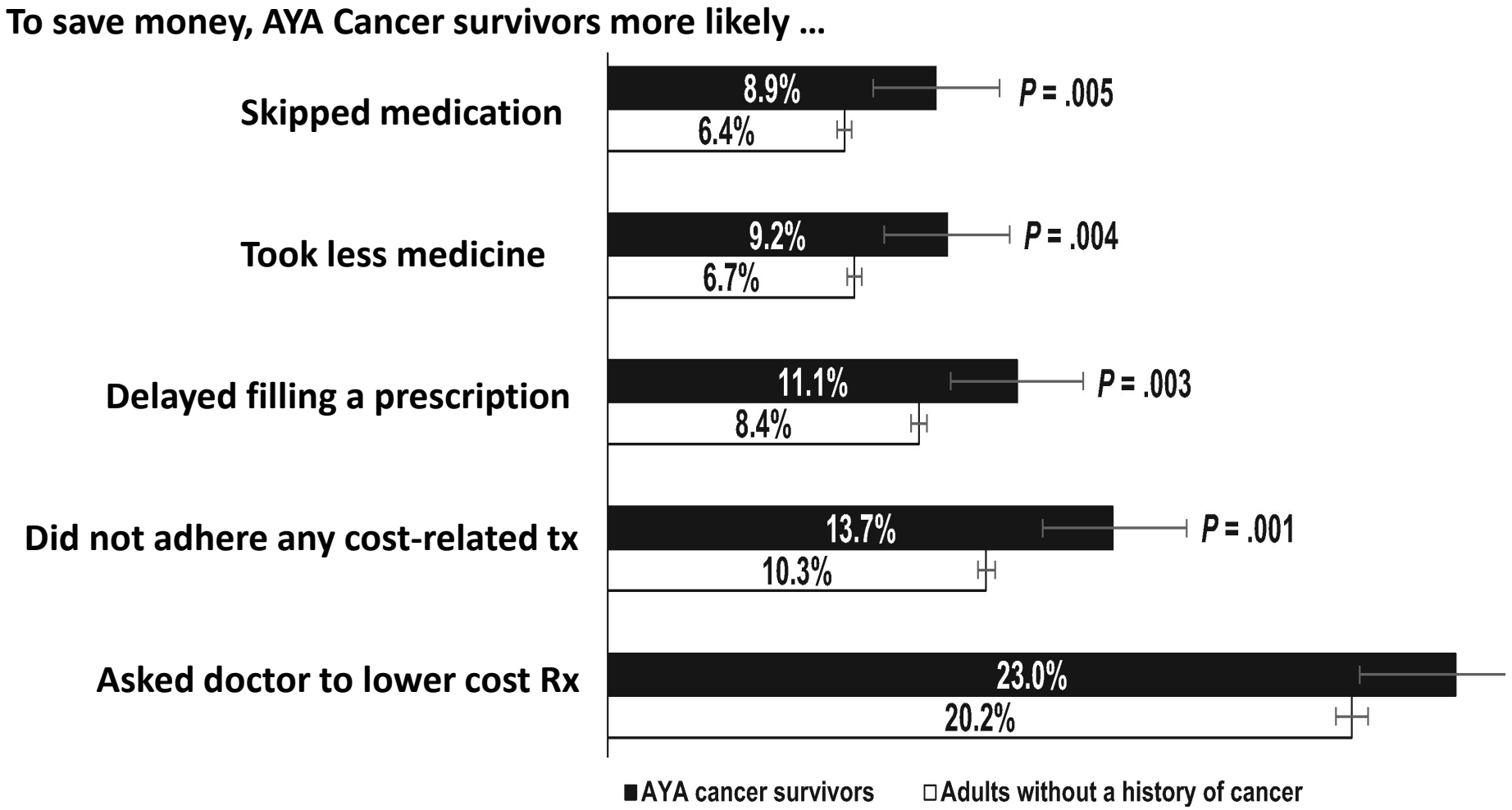
6. Late Effects of Treatment for Childhood Cancer (PDQ®)–Patient Version - National Cancer Institute

Increased risk of subsequent cancer(s)



Bright CJ et al. Risk of subsequent primary neoplasms in survivors of adolescent and young adult cancer (Teenage and Young Adult Cancer Survivor Study): a population-based, cohort study. The Lancet Oncology 2019 20531-545DOI: (10.1016/S1470-2045(18)30903-3)

Medical Financial Hardship Study



Lu AD et al. Medical Financial Hardship in Survivors of Adolescent and Young Adult Cancer in the US. J Natl Cancer Inst, Volume 113, Issue 8, August 2021, Pages 997–1004, https://doi.org/10.1093/jnci/djab013

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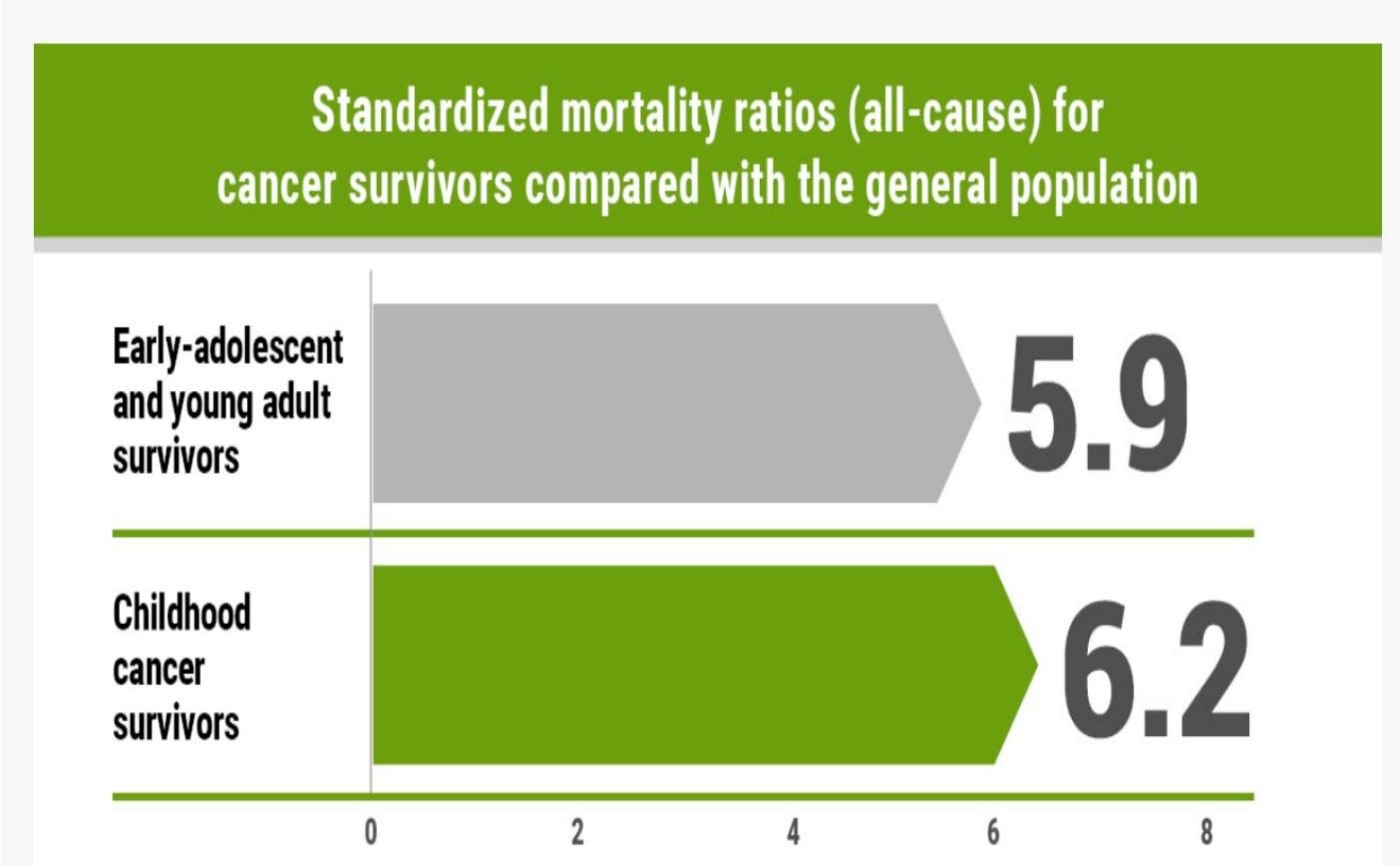
Higher risk for mortality



Suh E et al. Late Mortality and Chronic Health Conditions in Long-term Survivors of AYA Cancers: a retrospective cohort analysis form the Childhood Cancer Survivor Study. The Lancet Oncology 2020 March ; 21(3): 421-435.

Long -term and late effects of AYA Cancer survivors: non-cancer related

- Cardiovascular diseases, hyperthyroidism
- Brain and spinal cord: headache, dizziness, seizure, memory loss, movement disorder, nerve damage, pain, anxiety, depression,
- Effects on digestive, endocrine, immune, musculoskeletal, respiratory, sensory, urologic systems
- Reproductive complications
- Psychological
- Health insurance
- Financial hardship
- Shorter life expectancy than general population

- Ongoing studies for enough data on long-term quality of life and interventions

Late Effects of Treatment for Childhood Cancer (PDQ®)–Patient Version - National Cancer Institute

Challenges in PAYA cancer study

- ✓Heterogeneity of cancer type, risk factor and etiology
- ✓Rarity
- ✓Little known risk factors and etiology
- ✓Disproportionate knowledge by cancer incidence

- ✓Small state problem
- ✓Limitations of public health surveillance data

Acknowledgements

- **Local cancer registry partners in Rhode Island**
  - Newport Hospital
  - St. Joseph Health Services
  - The Miriam Hospital
  - Rhode Island Hospital
  - Roger Williams Medical Center
  - South County Hospital
  - Kent Hospital
  - The Westerly Hospital
  - Landmark Medical Center
  - Women & Infants Hospital
  - VA Medical Center
  - Maddock Ctr for Radiation Onc.
  - Southern New England Regional Cancer Center
  - South County Radiation Therapy
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  - Radiosurgery Center of RI
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Thank you!

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Palliative Care:
Optimizing Quality of Life across the Lifespan

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Partnership to Reduce Cancer in Rhode Island

Palliative Care:
Optimizing Quality of Life across the Lifespan

- A philosophy and approach to care
- Person-focused, family-oriented care that optimizes quality of life for the child or adult living with serious illness and their families by anticipating, preventing, and treating suffering
- Provided by an interdisciplinary team
- Comprehensively addresses and responds to physical, emotional, social, and spiritual needs of the child or adult and their family throughout the illness continuum

Partnership to Reduce Cancer in Rhode Island

Palliative Care:
Optimizing Quality of Life across the Lifespan

- An “extra layer of support”
- Appropriate at any stage of the disease
- Can be provided with curative and life-prolonging treatment or as the main focus of care
- Includes:
  - Developing a care plan
  - Establishing goals of care
  - Symptom management
  - Bereavement support

Partnership to Reduce Cancer in Rhode Island

Palliative Care:
Optimizing Quality of Life across the Lifespan

- Goals:
  - Optimize quality of life
  - Enhance communication
  - Assist with decision-making
  - Provide opportunities for personal growth

Partnership to Reduce Cancer in Rhode Island

Palliative Care:
Optimizing Quality of Life across the Lifespan